

**Access to Care for Acquired Brain Injury Survivors: A Critical Qualitative Inquiry**

by

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### **Abstract**

The purpose of this study was to examine the influence of language, power relations, and constructions of knowledge in shaping the experiences of acquired brain injury (ABI) survivors when accessing care. Using a critical qualitative inquiry, specifically the Foucauldian perspective, an in-depth semi-structured interview was conducted among 15 ABI survivors in Manitoba. The framework provided by Andersen's behavioural model of care (2008) was used to determine how ABI survivors experience access to care. Data were interpreted and discussed using deductive thematic analysis.

The findings from this analysis illustrate the role of power, knowledge, and language concerning disability related to the participants' access to care. In particular, the five interconnected themes (1) contextual characteristics domain, (2) individual characteristics domain, (3) perceived need, (4) power and knowledge nexus, and (5) language and power nexus in combination with the quantitative results of the pre-interview survey described the impact of the medicalization of brain injury on access to care. ABI survivors often face difficulties in meeting eligibility criteria owing to the invisible nature of the disability. This study's participants' unmet needs include access to community-based specialized services, quicker access to specialists/resources, service navigation support, and mental health services.

Furthermore, this study showed that healthcare and social service systems' multifaceted nature affected how ABI survivors perceived their disability, how the dominant discourses of ABI influenced the knowledge that is privileged, and how power was exercised within service navigation and service user-service provider interactions. This thesis concluded that access to care should be informed by shared knowledge construction between the service provider and service user.

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**Dedication**

To Kevin, my amazing husband, for the sacrificial care and support, without whom this work would not be possible.

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*In memory of my late thesis advisor, Dr. Laura Taylor, who started this thesis journey with me, may you rest in peace.*

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## Chapter One – Introduction

*The rage is relentless  
We need a movement with a quickness  
You are the witness of change and counteract  
We gotta take the power back (Rage Against the Machine, 1992)*

Acquired brain injury (ABI) is a significant public health issue. It affects individuals with brain injuries and those involved in their lives, such as family and friends (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2017). ABI is defined as damage to the brain that occurs after birth and is not related to a congenital disorder or a degenerative disease. (Brain Injury Canada [BIAC], 2019). In general, a brain injury can be categorized as (a) a traumatic brain injury (TBI) such as an injury resulting from falls, assaults, motor vehicle collisions, and sports injuries, (b) a non-traumatic brain injury (n-TBI), such as the effect of strokes, brain tumours, aneurysms, or meningitis, and (c), a mild traumatic brain injury (mTBI) such as concussions or post-concussive syndrome (BIAC, 2019). According to the International Paediatric Brain Injury Society ([IPBIS], 2016, p.2), “incidence data for non-TBIs relates to the illness or medical condition; the long-term disability from any resultant brain injury is rarely documented”. The prevalence of data available pertains to brain injuries from traumatic events. Dewan, Rattani, Gupta, Baticulon, Punchak, Agrawal, Adeleye, Shrimel, Rubiano, & Park (2018) estimated that globally, sixty-nine (69) million individuals suffer from TBI attributed to various causes each year, while 5.48 million of those incurs a severe TBI (Iaccarino, Carretta, Nicolosi, & Morseli, 2018).

A brain injury’s outcomes vary from complete recovery to death (Willemse-van Son, Ribbers, Stam, & Van de Boos, 2009). However, most ABI survivors continue to have long-term physical, cognitive, and psychosocial disabilities as their new reality (Willemse-van Son et al., 2009). For many ABI survivors, there is no physical indicator of impairment. Nevertheless, some may experience a range of physical and cognitive deficits such as loss of coordination, problems with memory retention, muscle rigidity, paralysis, epilepsy, difficulty in speaking, loss of sight, smell or taste, fatigue, reduced speed of information processing, and sexual problems (Holloway & Fyson, 2015). Though less easy to detect and assess, expected consequences linked to executive functions and behavioural and emotional changes are

reported by ABI survivors as having more impact on their quality of life (Holloway & Fyson, 2015).

Brain injury's impact is expected to rise with the population's ageing, which will increase the prevalence of people living with chronic illness and disability (Neurological Health Charities Canada [NHCC], 2014). According to the World Health Organization ([WHO], as cited by Hyder et al., 2007), "brain injury will surpass many diseases as the primary cause of death and disability by 2020" (p. 341). Brain Injury Canada (2019) estimates that an average of 100,000 individuals incurs a brain injury every year. It was projected that by 2031, the number of Canadians hospitalized with a brain injury would increase by 28% (NHCC, 2014).

Due to advances in medical science, more people with severe brain injury survive; thus, increasing the demand for health and social services (Quaglio et al., 2017). However, many who suffer a brain injury are not hospitalized yet left with impairments that limit their ability to function the same way as before the injury (Hodgkinson, Veerabangsa, Drane & McCluskey, 2000).

Healthcare services are often guided by disease-oriented epidemiology. As a condition, ABI presents a unique challenge regarding access to varying health and social services (Hodgkinson et al., 2000). According to van Balen (1996), "epidemiology aims to describe the frequency and patterns of distribution of disease, as well as to identify etiological factors in their pathogenesis for possible approaches to prevention and health administration" (p.4). Problems experienced by those living with an ABI are not always visible, it has often been referred to as "silent epidemic" present challenges in diagnosis and leads to difficulties in accessing care.

The disparate range of difficulties experienced by brain injury survivors is rarely physically manifested. Nevertheless, it requires a wide range of services over a long period. Service utilization studies show that services commonly accessed are predominantly related to physical difficulties, such as physiotherapy, speech pathology and occupational therapy (Thornhill et al., 2000, Corrigan et al., 2004; Ta'eed et al., 2017). However, research also suggests that mental sequelae such as cognitive and behavioural problems are among the more common issues faced by ABI survivors post-injury (Phillips et al., 2004; Hodgkinson et al., 2000; High Jr et al., 1995).

Anchored on data from prevalent literature, disability-oriented epidemiology often becomes the reference point for the comprehensive basis of health and community services

offered to brain injury survivors, including physical, behavioural, and cognitive rehabilitation (van Balen, 1997). Some healthcare providers' understanding of disability is based on the dominant medical perspective, whereby an individual living with a disability must have a visible impairment and limited functioning. However, the long-term sequelae associated with brain injury should also be regarded as a result of multifarious interactions between primary physical symptoms (disease-oriented) and secondary consequences (disability-oriented) resulting from disabilities and environmental reactions (van Balen, 1997). This dominant construction impedes the ABI survivor's experiences when seeking to access care services. According to Svestkova et al. (2010), disability should be approached to facilitate visible health status and include ABI survivors' limited functioning and disability. Moreover, an early and appropriate appraisal of an individual's disabilities would positively influence how the patient and environment reacts to them (van Balen et al., 1996).

There is an increasing amount of research on access to care. However, uncertainty remains as to the relationship between access and the service system's characteristics and policies (Goldsmith, 2007). Access to care research relies heavily on a quantitative, positivist paradigm that employs a hypothesis-testing approach. While this has answered questions on enhancing quality, improving health outcomes and service satisfaction, Goldsmith (2017) argues that the interaction between social structures and dominant constructions and the access to care is still not clearly understood. In other words, there is a need to study the context of accessing care from the lived experiences of individuals seeking care. There remains a gap in understanding the survivor's lived experiences in accessing health and social services (Eliacin, Fortney, Rattray & Kean, 2018). The goal is to learn from service users how social structures and individual characteristics in dominant knowledge impact health outcomes.

Therefore, it is crucial to recognize social structures and the dominant knowledge constructions of impairment and their manifestations on an individual with an ABI. Giving ABI survivors the voice and power to describe access to care helps illuminate systemic issues addressed by policy and practice change.

Thus, this study's purpose was to critically analyze and draw insights from ABI survivors' experiences related to access to care. Utilizing Andersen's behavioural model (Andersen, 2008), I examined the intersection between disability and differential access to care by conducting in-depth semi-structured interviews grounded by a critical disability lens from

service users' perspectives. By investigating and exploring the ABI survivors' lived experiences, this study aimed to provide a voice for the insider's knowledge of her or his condition and disability, which, in turn, depicts a better understanding of ABI survivors' experiences. This study may help professionals, especially social workers working in brain injury, develop a system to improve access to and service delivery quality.

### **Contribution to theory**

Despite an increasing amount of research on access to care and services, a gap remains between research and practice. Research and theory are envisioned to inform policy (Goldsmith, 2007). Therefore, there is a need to improve access and healthcare utilization models to build better policies.

Research on access to care and healthcare utilization seems to be locked in the quantitative, positivist, and dominant medical sciences field. Much of the literature available on health care access does not include the survivor's perspective and experiences (Dams-O'Connor et al., 2018).

The healthcare access model developed by Andersen and Aday 30 years ago has evolved in many iterations to adapt to today's system (Meade et al., 2014). The latest version of Andersen's Behavioural Model of Healthcare Utilization (Andersen, 2008) incorporated cultural and contextual factors to address healthcare quality.

While parity of access based on Andersen's model has been studied internationally (Willemsen-van Son, 2009), limited studies examine systemic and structural factors affecting brain injury survivors' care. This study utilized and adapted Andersen's behavioural model of healthcare (2008) by incorporating critical disability theory constructs of power/knowledge and language. Using Foucault's perspective, I explored how power/knowledge and language were exercised within the health and social services system in informing access to care.

Mantell, Simpson, Vungkhanching, Jones, Straandberg & Simonson (2017) assert that social work occupies an uncertain role in health care settings. The current political landscape is an opportunity for social workers to add to their practitioner identity through social work's contributions to new knowledge based on the social justice agenda in health. Social inclusion and health equity in service provision represent social work's commitment to social justice and empowerment principles (International Federation of Social Workers, as cited by Mantell et al., 2017). This study will incorporate critical disability studies to determine its applicability to

access theory models, such as Andersen's Behavioural Model of Healthcare Utilization (Andersen, 2008). Using critical disability theory's concepts of language, power relations, constructions of knowledge and structure, a broader interpretation of disability will be used to outline a more comprehensive model of access to care.

### **Contribution to social work practice and social policy**

There is an increase in the prevalence of people living with a disability, and lifetime impairment is increasing (Quaglio et al., 2017). The result is a rise in the demand for healthcare services and social, emotional, and psychological services to support their quality of life. Furthermore, social work's psychosocial approach and advocacy viewpoint support the legitimacy of a call to action for such needs as appropriate accommodations and social and financial support as essential issues in the continuum of care (Quaglio et al., 2017). Social work has been part of a multidisciplinary team of health and rehabilitation (Vungkanching & Tonsing, 2016). The increased importance of healthcare provision has shifted to interdisciplinary collaboration on individual and community health problems (Vungkanching & Tonsing, 2016). The complexity of ABI makes social work's contribution to the team even more pronounced and significant.

#### *Improved service provision*

This study has shown that disability is not just focused on the impairment, but also the societal barriers that preclude people with disabilities from living their full potential. Social workers are situated to advocate for improved services that will enhance the quality of life of those living with a brain injury. As social justice agents, social workers' critical role is to reconstruct the dominant discourses, especially in providing services through eligibility requirements. Increased knowledge of the invisible nature of brain injury and the impact of systemic and social structures on accessing care will give social workers a new perspective on how to best support ABI survivors.

#### *Improved policy response*

Despite universal coverage under the *Canada Health Act* (Government of Canada, 2019), societal factors play essential roles in access to care. Research has shown that despite removing economic barriers, inequities in health and social service utilization persist among disadvantaged, vulnerable populations (Martin et al., 2018).

This study identified that the biomedical evidence and dominant medical discourses inform eligibility criteria for services often sought and needed by ABI survivors. Policy developers and policymakers should acknowledge and account for the social impact of an impairment, such as a brain injury, to reduce health outcome disparities for this population. Also, policymakers should examine the complex and wide-ranging nature of brain injury and incorporate research that explains how needs are often unmet because of the nature of the condition when drafting policies and programs suitable for the population. While health and social services have embraced the value of evidence-based practice, policy developers should explore the service user's role as an abundant source of knowledge.

### **Situating the self**

I first walked into a support group meeting for brain injury survivors. I knew I wanted to research this topic from that moment onward and found myself on an enriching journey, especially while completing this thesis. Listening to brain injury survivors' lived experiences as a researcher deepened my understanding of brain injury and my appreciation for those who serve in the helping profession. As a disability, brain injury is fraught with misconceptions and is often misunderstood. This study developed my research skills and helped me critically reflect on their strengths and limitations.

I learned that research is not just a conduit but a contributor to policymaking. Hopefully, learning to understand the impact of the discursive practices on access to care for brain injury survivors may transcend boundaries for other invisible disabilities that have experienced the same disempowerment. I hope that the participants' voices will eventually translate into a reconstruction of what we know about disability, precisely brain injury.

Within my role, I have gained a better understanding of the knowledge I have access to. In my research, the qualitative interviews created a space to critically analyze the data using my social location as an immigrant woman and a person of colour. At the same time, I realized that I have an ethical and moral obligation to challenge the hegemonic discourses that impact brain injury survivors' access to services. A more accessible and coordinated brain injury service system would improve ABI survivors' lives and social participation. It is within social justice to help service users by challenging the current system's wide range of limitations and improving service coordination and provision. Critical disability theory, especially Foucault's

governmentality, enabled me to understand that, as a service provider, I am complicit in exerting power as a social actor in the regime of truth. Therefore, this thesis opened my eyes to be more cognizant of my role and power to reconstruct and redefine the dominant discourses that have disadvantaged people with disabilities.

### **Research Objectives**

Much of the research on ABI has focused on population health (Quaglio et al., 2017, Chan et al., 2013), rehabilitation (Colantonio et al., 2015; Cullen, 2008; Chen et al., 2012; CIHI, 2008) and clinical outcomes (Wilson et al., 2016; Kreutzer, 2002; Dams-O'Connor, 2018; Whitnall et al., 2006; McMillan et al., 2012; Corrigan et al., 2014) using administrative data and community surveys. This study focused on ABI survivors' lived experiences and their relationship to healthcare services. The study used critical disability theory as a theoretical underpinning, and Andersen's behavioural model was used as a framework in identifying facilitating factors and barriers to using healthcare services.

The purpose of this study was to examine the influence of language, power relations, and constructions of knowledge in shaping the experiences of access to care among ABI survivors. Specifically, access to care was examined in relation to gender, ethnicity, socio-economic status, and geographic location.

Specifically, the research objectives were:

1. To identify the factors that affect access to health and social service services.
2. To examine the role of variables such as language, power relations, and constructions of knowledge to access care from the perspective of individuals living with acquired brain injury.
3. To explore the interaction between contextual characteristics and individual characteristics and how it impacts equitable access to health and social services.

## **Chapter Two –Review of the Literature**

This chapter presents the literature review related to the main areas of research relevant to this thesis. First, it is crucial to define acquired brain injury, and disability since the underlying premise of investigating access to care rests on the assumption that having a disability from an ABI affects health care outcomes. Second, the broader literature on access to health care and the factors associated with equitable access are reviewed. Third, theoretical frameworks that shape the research methodology are discussed. Finally, the chapter concludes with a conceptual framework based on the literature reviewed and theoretical frameworks discussed, which would serve as the basis for this study's design.

### **Definition: Acquired brain injury**

ABI is an umbrella term that encompasses traumatic brain injury (TBI), non-traumatic brain injury (nTBI) and mild traumatic brain injury (mTBI). TBI includes open or closed injury to the head due to an external force such as motor vehicle collisions, falls, physical assaults, being struck by or against an object, and sports injuries (Brain Injury Canada, 2019). Non-traumatic brain injury results from causes such as vascular insults or stroke, anoxia, ruptured aneurysms, brain tumours, infections of the brain, and toxic poisoning (Manitoba Brain Injury Association [MBIA], 2018). According to the Evidence-based Review of Moderate to Severe Acquired Brain Injury ([ERABI],2018), “ABI typically involves a wide range of impairments affecting physical, neurocognitive and/or psychological functioning”.

Brain injury does not discriminate. It can happen to anyone, regardless of their age, gender, sexual orientation, ethnicity, and socioeconomic status. However, there is a paucity of information regarding the prevalence and incidence of acquired brain injury (ABI) due to inconsistent classification and injury reporting (IPBIS, 2016). Thus, any information available pertains to traumatic brain injury (TBI) and underestimates the global situation. According to IPBIS (2016, p.2), “incidence data for non-TBIs relates to the illness or medical condition; the long-term disability from any resultant brain injury is rarely documented.” Dewan et al. (2018) estimated that sixty-nine (69) million individuals are estimated to suffer TBI from all causes each year, with 5.48 million suffering a severe TBI (Iaccarino et al., 2018). In terms of non-



traumatic causes, Dewan et al. (2019) estimate that “each year there are 16.9 million cases of stroke and 30 million new cases of central nervous system infection” (p. 1086).

Hyder et al. (2017) posit that an individual with a brain injury is most likely to result in death and disability than all other types of injury (Hyder et al., 2017). The causes of ABI are diverse and wide-ranging. While the prevalence of non-TBIs is less documented, studies found that majority of traumatic brain injuries worldwide are due to road traffic injuries (60%), while 20% are due to falls, 10% is due to violence, while another 10% are due to work or sports injuries (Hyder et al., 2017). In Canada, the majority of hospitalizations for brain injuries involved males (63%), with the highest rates for those over 85 years of age, mainly due to falls (Public Health Agency of Canada [PHAC], 2020)

It is estimated that over 1.5 million Canadians live with some form of disability due to brain injury, with one person sustaining a brain injury approximately every three minutes (Northern Brain Injury Association, n.d.). Despite the prevalence of ABI, Brain Injury Canada (2019) cautions on the accuracy of statistics. Many injuries are often not reported at the time of the injury. In the province of Manitoba, ABI survivors use hospital services 3.9 times more frequently than people without ABI (Cameron, Purdie, Kliewer, & McClure, 2008).

While ABI survivors share the same impairments and life challenges as those with other chronic long-term conditions, they are distinct in terms of etiology. Furthermore, the lack of awareness of the complexity of brain injury among service providers, family members, and the public, in general, makes access to services more complicated.

According to a study published in *Lancet* (Maas et al., 2017), there is an immediate need to tackle the global health problem posed by acquired brain injury (ABI). Brain injury is “a public health challenge of vast but insufficiently recognized proportions” (Mass et al., p. 988). Quaglio et al. (2017) reported that ABI’s growing incidence had cost the global economy approximately \$400 billion annually. To reduce these enormous burden and societal costs of ABI, access to care, and prevention should be urgently addressed. It has been cited in research (Wilson, 2016; Quaglio et al., 2017) that ABI is the leading cause of death among individuals under 40. However, differences exist according to the epidemiology of ABI across different countries. For instance, in high-income countries such as Canada, an increased rate of older adults sustain ABI due to falls PHAC, 2020). While in low and middle-income countries, it was observed that the increase could be attributed to road traffic incidents (Wilson, 2016; Quaglio et

al., 2017). Further, Maas et al. (2017) suggest improving accurate epidemiological monitoring and robust health economic data to inform healthcare policy and practice.

As a condition, ABI is complex, which further strengthens the need for support guidelines and recommendations. ABI's diverse nature makes it challenging to individualize treatment. However, the one-size-fits-all approach has been the default approach (Quaglio et al., 2017). Before the advancement of medicine, an individual who sustained a severe brain injury would likely succumb to death.

### **Definition: Disability**

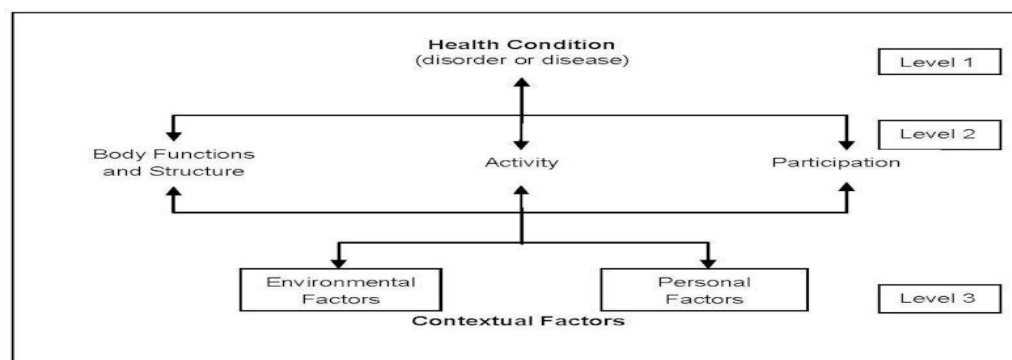
ABI is often referred to as a “hidden disability” as cognitive symptoms associated with the injury are more disabling in the lives of those who survive. However, the symptoms are not physically observable (Brain Injury Canada, n.d. 2019). Depending on the cause and severity of the injury, the trajectory of outcome varies. Frequently, recovery ranges from full recovery to persistent and severe impairment or gradual development of impairment (National Institute of Health, 2018). Long-term consequences can cause a high disability level for those in a persistent vegetative state (Brainline, 2019). Many ABI survivors experience neuropsychological, language, communication, and cognitive symptoms such as poor judgment, decreased executive function, memory loss, slow information processing, attention/concentration problems and lack of insight and awareness (MBIA, 2018). Rosario et al. (2017) posit that brain injury recovery is not linear and can be a slow, often prolonged process.

Various models have been proposed to explain and understand disability. Mitra & Shakespeare (2019) wrote, “how disability is conceptually defined has far-reaching social, economic, and political implications” (p.1). One of the most commonly used models was developed by the World Health Organization (WHO) titled the *International Classification of Functioning, Disability, and Health (ICF)*. ICF takes a biopsychosocial view of disability (WHO, 201, p. 8). This model was a revision of the previous International Classification of Impairments, Activities, and Participation (ICIDH-2) in response to criticism voiced by people with disabilities and the positive impact of the social model of disability. Within the ICF framework, functioning refers to abilities encompassing body functions (physiological functions of systems) and structures (anatomical parts), activities (execution of actions or tasks by an individual) and participation (World Health Organization, n.d., 2018). Furthermore, according to the World Health Organization (2002):

Disability is the umbrella term for impairments, activity limitations, and participation restrictions. It refers to the negative aspects of an individual's interaction (with a health condition) and that individual's contextual factors (environmental and personal factors).

The ICF framework (see Figure 1) views a person's functioning and disability as a “dynamic interaction between health conditions and contextual factors, which include personal and environmental factors” (WHO, 2001, p.8). On the other hand, personal factors include gender, race, age, fitness, lifestyle, and coping styles. Environmental factors include physical, social, and attitudinal environments (WHO, 2001). The ICF Framework's goal is to measure a health condition such as ABI, on body function and structure, on activity limitation and participation restriction or stated simply, the person's functioning in day-to-day life (WHO, 2001). The ICF works both as a conceptual model adopted in public health curricula and clinical associations and as a classification framework used in rehabilitation settings for functioning and disability (Mitra & Shakespeare, 2019).

*Figure 1: International Classification of Functioning, Disability, and Health (ICF) Framework*



*Figure 1: International classification of functioning, disability, and health (ICF). Reprinted from World Health Organization, 2002. Copyright 2002 by the World Health Organization. Reprinted with permission.*

According to Angeloni (2013, p.4)

disability involves any dysfunction of impairments, activity limitations or participation restrictions. The arrows indicate that components of health are interlinked and affect each other. This framework responded to the critiques of those advocating a more social model of disability, which questions the linear relationships implied by the ICIDH-2.

WHO's World Report on Disability estimated over a billion people or 15% of the world's population living with a disability (2011). This report suggests that disability is not a marginal, but a growing phenomenon.

The WHO defined disability as “the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives” (WHO, 2011, p.17).

Berghs et al. (2016) suggest that the broadened definition of disability by the ICF acknowledges the social and physical environment's role in disability discourses while simultaneously recognizing the disabled people's rights and citizenship. People with disabilities face risks associated with their disabling health conditions. However, these risks are exacerbated by structural factors such as poor physical and social environments. (Shakespeare, Bright & Kuper, 2018). In considering the health outcomes, Shakespeare et al. (2018) postulate that “structural factors are as important as risks associated with having a disabling health condition (p. 26). The physical and social environment can worsen the consequences of living with a disability, accentuating the disabling conditions. (Shakespeare et al., 2018).

Furthermore, the lack of healthcare access leads to poorer health outcomes among people with disabilities (Shakespeare et al., 2018). Both men and women with disabilities were significantly more likely to report needing healthcare services but not receiving them than people without disabilities (women: 5.8% versus 3.7%; men: 5.8% versus 4.1%) (Shakespeare et al., 2018). Mccoll, Jarzyrowska & Short (2010) found that Canadian adults with disabilities aged 20-64 had three times the level of unmet healthcare needs as adults without disabilities. Shakespeare et al. (2018) propose that “health outcomes are likely to be worse for some persons with disabilities because some impairments inevitably limit life expectancy so that there is unlikely ever to be complete health equality” (p. 29).

People who acquire a disability such as those with brain injury, often find it difficult to express their needs for help. Perhaps, this could be because they do not recognize their impairment as permanent (Moretti, 2017). At the same time, ABI survivors often have fewer apparent disabilities or visible physical manifestation of disabilities. Olney and Kim (2001) suggest that the invisible nature of a hidden disability such as a brain injury can present barriers to access to services because they may be considered less deserving and less

significant than more visible disabilities (Olney and Kim, 2001). They further argue that misconceptions and other people's assumptions and attitudes can strongly influence how individuals with invisible disabilities perceived themselves. Consequently, this self-perception will likely cause the individuals to feel guilt, anxiety, self-doubt, and ambivalence, especially toward receiving assistance and services (Olney and Kim, 2001).

Furthermore, people with cognitive disabilities, such as ABI survivors, may not have been previously involved with the disability environment and may not be equipped to counter the negative messages (Olney & Kim, 2001). In this regard, "people with hidden disabilities may exist in a netherworld, belonging solidly to neither the 'disabled' nor the 'non-disabled' group" (p. 564).

**Definition: Access to Care**

Access to healthcare is a prerequisite to achieving health equity. As expressed in the International Covenant on Economic, Social and Cultural Rights (Office of the Commissioner of Human Rights [OCHR], 2002) and reiterated from a disability perspective in the Convention on the Rights of Persons with Disabilities, access to care is a question of the realization of human rights (Shakespeare et al., 2018). Shakespeare et al. (2018) argue that "the most extensive human rights violation in the context of health services is the failure to meet health needs or to meet health needs in appropriate ways" (p.30).

The political environment and its realities influence the definition of access as it is closely aligned with policy (Goldsmith, 2007). The *Canada Health Act* sets the standards to provide universal health coverage to all citizens (Government of Canada, 2001). According to Martin et al. (2018), "the healthcare system is less a true national system than a decentralized collection of provincial and territorial insurance plans covering a narrow basket of services, which are free at the point of care" (p.1718).

However, access is not defined but simply regarded as "the absence of explicit financial barriers for medically necessary services" (Government of Canada, 2001, para 1). According to Health Canada (Government of Canada, 2001, para 2), "equity in health refers to the fair and just distribution of services." while access or utility is defined as "availability of service" (Government of Canada, 2001). Therefore, equitable access is defined as "the provision of health services in a way that provides an equal opportunity for

all citizens to achieve maximum health” (Government of Canada, 2001, para 2). Canada’s universal health coverage (UHC) is considered one of the best globally (Martin, Miller, Caron, Vissandje & Marchildon, 2018). According to WHO (as cited by Shakespeare et al., 2018), “UHC means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship” (p.11). However, despite addressing financial barriers to healthcare access, “persistent inequitable access to health services in both public and private systems and the urgent need to address health disparities for a vulnerable population and Indigenous Canadians” remains an issue (Martin et al., 2018, p. 1719).

Access to care has a variety of nuanced definitions. It is a concept that has received various interpretations by policymakers, researchers, and the general public (Bowen, 2000). Pechansky and Thomas (as cited in Meade et al., 2014) defined access in terms of the five ‘As,’ namely: affordability, availability, accessibility, accommodation, and acceptability.

Affordability relates to how the provider’s charges relate to the client’s ability and willingness to pay for service. Availability is the extent to which the provider has the requisite resources to meet the needs of the client. Accessibility refers to geographic proximity and is determined by how easily the client can physically reach the provider’s location. The accommodation reflects the extent to which the healthcare service is provided in a way that meets the needs, constraints, and preferences of the client. Finally, acceptability refers to the reciprocal relationship between the provider and client and their level of comfort as related to fixed characteristics (Meade et al., 2014, 634).

Access to care in Canada rests on the notion that “access to care should be based on need, not on ability to pay, is a defining national value” (Martin et al., 2018, p. 1718). However, primary care physicians are considered the focal point of health service delivery. They are given the vital role of “gatekeepers” to other specialized services and hospital care. Therefore, access to care can be influenced by financial barriers and relationships with service providers. The “lack of attention to other non-price factors that might be expected to influence the demand and supply of care appears to imply that those service provision free at the point of delivery is a sufficient condition for ‘reasonable accesses to services’” (Birch et al., 1996, p.6.).

The majority of published research attempts to measure access have used utilization related to income and health (Bowen, 2000). Research surrounding access to healthcare across

the Canadian population was based on the Medicare program's philosophy that ensures Canadians of all income levels have equal access to (use of) care (Bowen, 2000).

In most literature, utilization data appear to be mainly the most widely used because it is a few forms of data readily available (Bowen, 2000). Measuring access based on utilization discounts access as a relevant experience that involves the availability of services, relationship with service providers, cultural and contextual sensitivity of the service, and other factors related to care provisions.

Recognizing the importance of other factors to measure access, definitions of access have evolved to "incorporate notions of fit among personal, sociocultural, economic, and system-related factors that enable individuals, families, and communities to have timely and needed access to care" (Meade, Mahmoudi & Lee, 2014, p. 29). This interaction between individual and environmental factors was presented in a framework by Aday and Andersen (1974), which defines access to care as "the use of service as a function of predisposing, enabling, and need-related factors" (Aday and Andersen as cited by Meade et al., 2014, p. 632). Within this model, access to care was defined as the availability of services that meet the consumer's needs, both perceived and evaluated. However, one noticeable shortcoming in this model is the lack of consideration for cultural and contextual factors, which may prove challenging to account for in services to vulnerable populations, such as ABI survivors. Andersen (2008) responded to the original model's criticisms through his latest iteration of the behavioural model that defines access as

the actual use of personal health services and everything that facilitates or impedes their use. It is the link between health services systems and the populations they serve. Access means not only getting to service but also getting to the right services at the right time to promote improved health outcomes (p.3).

This definition of access connected the three health policy objectives of health service use, social justice, and health service delivery effectiveness and efficiency (Goldsmith, 2007). The expansion of this new model of access incorporated contextual aspects and added a component representing provider-patient interactions.

The majority of literature reviewed in this study defines care interchangeably with healthcare utilization and/or service utilization.

### Studies of Utilization

There is a limited number of Canadian qualitative studies using the ABI survivors' perspective. This review includes literature relevant not only to Canada but also to other developed countries.

Table 1

#### *Utilization studies*

| <b>Author/Year<br/>Region</b>        | <b>Purpose</b>  | <b>Findings</b>   | <b>Type of<br/>Utilization</b>    |
|--------------------------------------|---|---|-----------------------------------|
| Baptiste, B. et al. (2015)<br>Canada | <p>The study had two-fold objectives: (1) to describe the impact of accessing case management (CM) among TBI survivors and (2) factors associated with using CM service.</p> <p>Design: retrospective cohort, with a nested case-control design</p> <p>N=476</p>  | Using Andersen's behavioural model framework, findings revealed that younger, less educated patients and those living in a facility use more CM services than older, more educated and those living alone counterparts. | Case Management/Care Coordination |
| Bazarian et al. (2003)<br>USA        | <p>To investigate the management and variation of care for individuals with mild traumatic brain injury who access the Emergency Department (ED) services.</p> <p>Design: Secondary analysis of Emergency Department (ED) survey conducted from 1998-2000</p> <p>N= 878 (representing 4.1 m ED visits annually)</p> | Findings of the study identified variation in ED care with individuals discharged without recommendations for follow up.  |                                   |



|   |  |  |   |
|---|--|--|---|
| High Jr. et al.<br>(1995)<br><br>USA          | To examine productivity and access to medical and rehabilitation services following TBI<br><br>Design: Quantitative survey<br><br>N= 763   | Service utilization varied across age, gender and educational level. While productivity is affected by several factors, results revealed a general increase in productivity associated with advancing age ( up to 55) and higher educational level | Medical, Rehabilitation, Vocational utilization |
| Hunt et al.<br>(2016)<br><br>Canada           | To describe the type, intensity, and estimate costs of healthcare provider visits following mTBI in Ontario.<br><br>Design: Survey<br><br>N= 201 adults with mTBI                                    | 15% of mTBI patients received tertiary care. Accurate and timely diagnosis is needed for early coordination and follow-up care for those needing tertiary care.  | Tertiary care                                   |
| Hodgkinson, A. et al. (2000)<br><br>Australia | To document service utilization by people with TBI at different times post-injury and identify factors that predict service use.<br><br>Design: Cross-sectional design<br><br>N= 119 adults with TBI | 81% of the sample used medical and allied health services and 66% used transportation services, and 40% used vocational rehabilitation services  | Medical, Rehabilitation, Vocational utilization |
| Jourdan, C. et al. (2015)<br><br>France       | To assess brain injury service utilization and its determinants using Andersen's model.<br><br>Design: Prospective Inception Cohort study<br><br>N= 504 adults with severe TBI                       | Service utilization was dependent on need factors such as injury severity, more than predisposing and geographical factors.  | Medical and rehabilitation utilization          |

|  |   |   |   |
|--|---|---|---|
| Phillips et al.<br>(2004)<br><br>USA       | <p>The study aimed to examine service utilization among ABI survivors during the first three months of inpatient rehabilitation discharge.</p> <p>Design: A prospective follow-up study.</p> <p>N= 113</p>                  | Findings show that the intensity of service use and not the severity of the injury as a predictor of medical and rehabilitation utilization.  | Medical and rehabilitation utilization        |
| Prang, K et al.<br>(2012)<br><br>Australia | <p>To describe the type, intensity and direct cost of healthcare and disability services used following transport-related traumatic brain injury (TBI).</p> <p>Design: A retrospective cohort study</p> <p>N= 423 cases</p> | The severity of injury determined the intensity of service use. The severe TBI group had the highest total of services.   | Healthcare and disability service utilization |
| Salisbury, D.<br>et al. (2017)<br><br>USA  | <p>To explore hospital-based health care utilization after admission to a level I trauma centre after mild traumatic brain injury (TBI)</p> <p>Design: Retrospective review</p> <p>N= 5291 cases</p>                        | 66% of the sample had hospital readmissions in the first year post-injury, with 95% accounting for urgent and procedural visits. However, a steep decline in utilization occurs after the first year and in subsequent years. | Hospital readmission                          |
| Schatz et al.,<br>2001<br><br>USA          | <p>To determine factors affecting access to neuropsychological evaluations following TBI</p> <p>Design: Retrospective case review of administrative data</p> <p>N= 273 cases</p>  | Recipients of NPE were mostly younger, more likely to be involved in liability claims, had higher functional ability in primary rehabilitation and attended multiple rehabilitation facilities                                | Neuropsychology utilization                   |

|   |   |  |  |
|---|---|--|--|
| Ta'eed, G. et al. (2011)<br><br>Australia | To investigate factors determining service utilization in a population-based sample with injuries ranging from mild to severe, including cases of not hospitalized patients.<br><br>Design: Retrospective review of clinical case files<br><br>N= 175 | More prolonged post-traumatic amnesia and previous TBI were associated with increased service intensity. Findings also show that nursing, psychology and social work were associated with a large proportion of referrals. | Rehabilitation and Neuropsychology utilization |
|---|---|--|--|

The complexity and long-term consequences of ABI suggest that survivors need access to healthcare services. However, there is limited data on the evidence of healthcare utilization among the ABI population. In Canada, Hunt et al. (2016) investigated the types and intensity of healthcare provider visits among mild Traumatic Brain Injury survivors in Ontario. The study revealed that only 15% of patients (n=201) received tertiary care from specialists. Hunt et al. (2015) posit that with an average waiting period of 10 months before their tertiary care visit, patients had to consume 6794 healthcare provider visits while waiting. These visits cost approximately \$500,000 (Canadian dollars) before mTBI survivors were even admitted to tertiary care.

Further, the study reported that mTBI survivors are as likely as those with severe brain injury to access various services. This indicates that early identification and diagnosis for this population will lessen services' direct costs (Hunt et al., 2016). Nevertheless, the investigators were aware that the study population might have been more biased towards mTBI survivors who had more significant injuries, thereby translating into higher healthcare utilization. It is important to note that this study was conducted in Ontario. Because the cost per visit differs across provinces, Manitoba may have different rates compared to Ontario.

Another recent Canadian study on service utilization zeroed in on the use of case management in Ontario. Case management emerged as an essential health service, especially for complex and evolving TBI (Baptiste et al., 2015). Using Andersen's behavioural model framework, a retrospective cohort with a nested case-control design using n=476 datasets (Baptiste et al., 2015) found that younger, less educated survivors and those living in a facility

use more case management services compared to older, more educated survivors, and those living alone. While the results may prove interesting, the authors argue that educated and older people can advocate for themselves more than the younger survivors, resulting in the lack of need for case management service. Also, this study did not capture case management availability in a person's region of residence. In Manitoba, outside of in-patient rehabilitation centres and the local brain injury association, case management is also not available.

In contrast, Hodgkinson et al. (2000) found that survivors use various services at different phases of their injury. Using a cross-sectional design among four subjects (n=119), 81% of survivors used medical and allied health services. In contrast, 66% used transportation and 40% used vocational rehabilitation. Correspondingly, service utilization remained high at six months, 18 months, and even 17 years' post-injury. Although a decline in service utilization was observed in the first five years, an increase was also evident five to ten (5-10) years post-injury. Researchers found that although severities of injury and physical, cognitive, and psychosocial disabilities were all predictors of service utilization. But psychosocial disability predicts ongoing service utilization regardless of severity and years following the injury.

These findings are consistent with those in a study by Schatz et al. (2001). The study had a sample of 273 individuals with a TBI and in need of psychological and disability services. Only 26% received a neuropsychological evaluation (NPE). While neuropsychological tests are often used to estimate the eventual outcome or recovery path following an ABI, Schatz et al. (2001), found that only 26% of the sample received a neuropsychological evaluation. NPEs are meaningful in presenting a picture of the survivor's overall assessment by integrating the strengths and weaknesses into concrete recommendations, crucial for rehabilitation planning and recovery. In the study, those who received an NPE were mostly young, more likely to be involved in liability claims, and most likely to have achieved higher functional rehabilitation and attended multiple rehabilitation facilities (Schatz et al., 2001). These findings support Ta'eed et al.'s (2011) study, which investigated factors associated with service utilization (n=175) in Australia's retrospective study. Findings revealed that patients suffering from more severe brain injury utilized more medical and rehabilitation services.

In contrast, patients with mild TBI and post-concussive syndrome sought psychological and social work services. This suggests that the severity of injury predicted its utilization of medical and rehabilitation services, but not for other services such as psychological and

disability-related. By comparison, Phillips (2004) measured utilization at a certain period of recovery. Phillips found that at the first three post-rehabilitation discharges, at least 80% saw their physicians, 42% visited their physicians more than four times, over 50% attended day rehabilitation programs, 42% received physical therapy, 36% occupational therapy, 33% speech pathology, and 11% received psychological counselling (Philips et al., 2004). Re-hospitalizations related to seizures and psychiatric disorders were 12% higher and rose to 19% within five years (Philips, 2004). The findings described in this study were based on an ABI population that attended in-patient rehabilitation in a specific statewide model system (Georgia, USA), which may not yield the same results for survivors who did not undergo inpatient rehabilitation specifically from a different geographical location like Manitoba.

Conversely, Bazarian et al. (2005) investigated a national study looking at the emergency department (ED) management of isolated mild traumatic brain injury. The study's results reported several areas of deficient care with 44.3% were found to have received Computed Axial Tomography (CT scan), 23.9% other non-extremity, non-chest x-rays, 17.1% wound care and 14.1% IV fluids (Bazarian et al., 2005). Almost 38% of the ED population were discharged from the ED with underreported and untreated pain. (Bazarian et al., 2005, p., 473). These findings suggest that the lack of guidelines on what constitutes a mild TBI affects access to ED care.

Service utilization appears to be sample dependent; in some studies, physical and cognitive assistance services are higher with severe brain injury. On the other hand, those with a less severe injury such as mild TBI are more likely to use psychological and social work services. Therefore, heterogeneity of injury severity is vital in understanding access to healthcare among the brain injury population.

### **Studies on Factors Associated with Access to Care**

Table 2

*Factors Affecting Access to Care*

| <b>Author/Year/<br/>Region</b> | <b>Purpose</b> | <b>Findings</b> | <b>Factors</b> |
|--------------------------------|----------------|-----------------|----------------|
|--------------------------------|----------------|-----------------|----------------|

|   |   |  |                              |
|---|---|--|------------------------------|
| Alban et al.,<br>2010<br><br>USA          | To investigate the effects of healthcare insurance on TBI outcomes<br><br>Design: Retrospective Case Review within the National Trauma Bank<br><br>N: 52,344 moderate to severe TBI   | Insured patients had more prolonged ICU stays in an unadjusted analysis  | Insurance and access to care |
| Bowman, S. et al. (2007)<br><br>USA       | To examine racial differences for patients with severe TBI<br><br>Design: Retrospective case review using National Trauma data bank<br><br>n= 175   | Results revealed racial disparities in both mortality and pattern of hospital discharges. Hospitalization rates are higher for people of colour, but they receive fewer rehabilitation therapy services than whites.   | Race                         |
| Callender, L. et al. (2017)<br><br>USA    | To examine the impact of race and ethnicity on healthcare utilization among TBI patients<br><br>Design: Retrospective cohort<br><br>N= 4,150 TBI patients admitted between January 2003- June 2014  | Race and insurance accounted for healthcare utilization with considerable difference between Non-Hispanics with insurance and Hispanics with insurance. Patients who belong to the Non-Hispanic Black with public insurance were at the most significant risk. | Race and insurance           |
| Haag et al. (2016)                        | To explore and gain insight on access to care experienced by women living with an acquired brain injury, caregivers, and health care professionals.<br><br>Design: A qualitative pilot study using a descriptive, interpretive methodology<br><br>N= 16 | The study results revealed the interaction of gender roles and disability on the wellbeing and health of women with ABI.   | Gender                       |
| Keightley, M. et al. (2009)<br><br>Canada | To explore the experiences of health care practitioners working with Aboriginal clients recovering from   | Results showed the lack of protocols on rehabilitation and discharge planning for ABI survivors living in the  | Race<br>Culture              |

|  |  |   |                        |
|--|--|---|------------------------|
|  | <p>Acquired brain injury (ABI).</p> <p>Design: Participatory Research Design</p> <p>N= 14</p>  | <p>reserve/remote communities. Factors associated with geographical location and socioeconomic status increase the risk of poor outcomes for Aboriginal survivors.</p>  |                        |
| <p>Kumar et al. (2019)</p> <p>USA</p>              | <p>To assess the relationship of acute complications, pre-existing chronic diseases, and substance abuse with clinical and functional outcomes among adults 50 years and older with moderate to severe TBI</p>   | <p>Among 50 years and older adult survivors, service utilization was higher for pre-existing health conditions and acute complications.</p>   | Age                    |
| <p>Mitsch et al. (2014)</p> <p>Australia</p>       | <p>To investigate the differences in access to care for ABI survivors living in rural and remote areas of New South Wales, Australia.</p> <p>Design: Exploratory and Descriptive Qualitative Research</p> <p>N= 72 (59 service providers, 6 ABI survivors, and seven caregivers).</p>                | <p>Access to care for ABI survivors living in remote and rural area was impacted by (1) long distances to brain injury rehabilitation, (2) lack of appropriately skilled staff in the area, (3) existing gaps in service delivery, and (4) lack of culture-specific services for the Aboriginal people.</p> | Geographic location    |
| <p>Redpath et al. (2010)</p> <p>United Kingdom</p> | <p>To investigate the relationship between healthcare professionals' attitudes and intended healthcare behaviour towards ABI survivors.</p> <p>Design: Independent Groups design</p> <p>N= 460 participants (131 trainee nurses, 94 qualified nurses, 174 trainee doctors, 61 qualified doctors)</p> | <p>The presence of prejudicial attitudes was identified among healthcare professionals when ABI survivor's cause of injury was deemed their fault. Within healthcare professions, more qualified doctors and nurses expressed higher prejudice than those new to the profession.</p>                        | Attitudinal/Stereotype |

|   |   |   |                           |
|---|---|---|---------------------------|
| <p>Sample &amp; Darragh (1998)</p> <p>USA</p> | <p>To examine access to care among women with ABI.</p> <p>Design: Qualitative research</p> <p>N= 10</p>   | <p>Regardless of geographical location (rural vs urban), all women experienced difficulty obtaining an ABI diagnosis. Problems with service providers and service systems, financial challenges, travelling for services, lack of information or services in their area, and lack of care coordination were identified as barriers to accessing care.</p> | <p>Gender</p>             |
| <p>Selassie et al. (2004)</p> <p>USA</p>      | <p>To examine the effect of insurance status and demographic characteristics on the likelihood of hospital admission among TBI survivors who presented themselves at the Emergency Department (ED) for treatment.</p> <p>Design: Retrospective design using data sets</p> <p>N= 70, 671</p> | <p>Injury severity and pre-existing health status remain the strongest predictors of hospital admission following TBI. However, results revealed the uninsured black females were less likely to be hospitalized.</p>   | <p>Race<br/>Insurance</p> |
| <p>Toor et al. (2016)</p> <p>Canada</p>       | <p>To explore long-term healthcare utilization and access to services among women with ABI.</p> <p>Design: Retrospective cohort study using the Canadian Community Health Survey</p> <p>N= 210 (105 with TBI, 105 without)</p>  | <p>Results showed that women with TBI were twice likely to utilize family physician and community health services than women without TBI. Both women with TBI and without reported barriers in access to care but women with TBI face higher rates of financial and structural barriers.</p>  | <p>Gender</p>             |



|  |  |  |  |
|--|--|--|--|
| Willemse-van Son, A., Ribbers, G., Stam, H., and van de Bos, G. (2009) | To examine equity in long-term healthcare utilization among brain injury survivors using Andersen's model of healthcare utilization. | Findings revealed that health-related needs explained most of the utilization of survivors who needed care, received care. However, equity could not be established as predisposing characteristics such as the individual's health beliefs impact =utilization of services. | Physician and supportive care utilization in TBI in the Netherlands. |
| The Netherlands  | Design: Cross-sectional study<br><br>N= 79   |  |  |

Andersen's Behavioural Model of Health Services use (2008) identified several factors related to health care utilization. Based on the model's latest iteration, the factors can be categorized as contextual characteristics, individual characteristics, health behaviours, and outcomes (Andersen, 2008).

### **Contextual characteristics**

Contextual factors are often systemic and relate to accessibility and services (Andersen, 2008). An extensive literature on insurance coverage and its effects on health care utilization and its effects have received extensive research interest.

Canada's universal health care coverage attenuates disparities in health care as services are generally free to provide equitable access to care for all residents (Wellstood, Wilson, & Eyles, 2004). Although Canada's access to care continues to see differences in health care utilization based on personal factors, universal coverage is not sufficient to remove health inequities, especially nonfinancial barriers such as cultural and language barriers. (Lasser et al., 2006; Wellstood, 2004).

While universal health coverage removes the direct costs of seeking care, it does not consider the indirect costs, such as the cost of transportation and taking time off from work, which may prevent individuals from seeking care (Wellstood, Wilson, & Eyles, 2006).

Research on health care access in Canada is primarily contextualized within the population health perspective (Wellstood et al., 2006). Furthermore, access to care is also shaped by system-related factors such as policies stipulated under the CHA. In turn, these system

barriers influence the health care system's structure or organization of services on access or, more specifically, the health care system's constraints that can obstruct the use or delivery of services (Wellstood et al., 2006). While CHA removed direct costs for health care access, individuals facing systemic and structural barriers may experience opportunity costs such as taking time off work, transportation, geographic factors in the process of obtaining care (Wellstood et al., 2006). According to Lasser, Himmelstein & Woodhandler (2006), Canadians under universal healthcare fare better than their American neighbours. Individuals living in the US are less likely to have a regular medical doctor, more likely to have unmet health care needs, and more than twice likely to forgo needed medicines (Lasser et al., 2006). While both countries share health disparities based on race, income, and immigrant status, it appears to be more pronounced in the United States (Lasser et al., 2006).

Selassie, Pickelsimer, Frazier & Ferguson (2004) identified the importance of insurance status and demographic factors as determinants of hospital admission among individuals who incurred a brain injury. Using retrospective data sets (N= 70, 671), Selassie et al. (2004) found that the strongest predictors for hospital admission were the severity of the injury and pre-existing health conditions. However, when variables for race and gender were controlled, black females without insurance were less likely to be admitted than those privately insured (Selassie et al., 2004). Another US study by Alban et al. (2010) investigated healthcare insurance's effects on TBI outcomes. Findings from this retrospective study of n=52, 344 revealed that insured patients had more extended hospital stays than those who did not have insurance. Similarly, Crandall et al. (2014) supported the same findings among mild TBI survivors (N= 190). They found that being insured increases the likelihood of follow-up and referral to specialist care.

Another contextual characteristic that has been associated with access to care is geographic location. In examining access to care, Rosenberg and Hanlon (1996) suggest incorporating the "health service environment", which refers to "whether one live in rural or urban areas, population density, the availability of health care providers and the types of services offered" (p. 976). Disparities in access between urban and rural areas have been a problem for many years in Canada (Sibley & Weiner, 2011). The most significant degree of inequality between rural and urban residents is access to specialist services, as the latter are frequently located in bigger cities. *"If there is two-tiered medicine in Canada, it is not the rich and poor, and it is urban versus rural."* These were the words of Health Canada's Special Advisor on

Rural Health, describing the increasingly dire circumstances facing rural Canadians concerning health care access (Laurent, 2002).

A national survey was conducted to identify adult trauma centres' locations and capabilities across Canada and identify the catchment populations they serve. Hameed, Schurman, Razek, Boone, van Heest, Taulu & Simons (2010) reported that geographic disparities exist in accessing care. Further, the survey revealed that most Canadians (77.5%) residing within a 1-hour road travel catchment area of Level I and Level II trauma centres had access to services while 22.5% who live more than an hour away were residing in rural and remote regions. While the study reported established access to high-quality acute trauma care, it also magnified the urban/rural divide. In Manitoba, a Level I trauma centre is provided by the Health Sciences Centre (HSC). The centre serves Manitoba, including the territory of Nunavut and Western Ontario. Level I Trauma centres are an essential aspect of the chain of survival, especially of ABI (ERABI, 2019). Lasry, Dudley, Fuhrer, Torrie, Carlin & Marcoux (2016) found that individuals living in the rural regions have a higher likelihood of injuries and poorer health outcomes than those living in the urban region. Research has shown that the faster the treatment and intervention are provided, the less devastating the impact and the better the recovery (ERABI, 2019).

In Canada, Indigenous populations generally have poorer health status, with "far-reaching inequities in the social determinants of health that even the best healthcare systems cannot redress" (Martin et al., 2018, p. 1729). Specifically, TBI explains a significant proportion of injuries among Indigenous North American populations (Lasry et al., 2016). Further, the mechanisms of injury related to TBI are different when comparing rural and urban environments where Indigenous populations live (Lasry et al., 2016). A retrospective population-based cohort study of patients with TBI admitted to hospitals in Quebec, stratified by health region, from 2000-2012 revealed 172 TBI hospitalizations covering the twelve years (Lasry et al., 2016). The study found that ABI survivors living in a region's remote community were associated with higher hospital admission rates and the most severe injuries. Lasry et al. (2016) suggest that the mechanism of injuries could be attributed to individuals having to travel more distance and using off-road vehicles due to lack of access to provincial roads. Also, generalizations based on other Indigenous communities' findings should be undertaken with caution since the setting's population structure (Terres-Cries-de-la-Baie-James) is substantially

different from the rest of the province of Quebec, and more so in Manitoba. Though this study used administrative data, Lasry et al. (2016) completed meticulous and detailed data collection by reviewing charts and obtaining information regarding the evolution of the patient's injuries.

Another Canadian study using a qualitative participatory research design was conducted among 14 health care practitioners working with Aboriginals recovering from ABI (Knightley, Ratnayake, Minore, Katt, Cameron, White & Colantonio, 2009). Using the framework method of analysis, the results uncovered that the key challenge faced by Aboriginal ABI survivors was the lack of protocols for rehabilitation and discharge planning in reserve and remote communities. Other challenges included difficulty of travel and socio-cultural factors associated with post-acute care. Though the study was conducted among service providers, an extensive collaboration between traditionally defined researchers and the community was utilized in each research study to identify the problem, disseminate results, and educational and action plans of the study (Knightley et al., 2009).

Location is another factor that affects rural residents and Aboriginal communities, whose residences are often located in the remote and northern parts of the province. The report entitled *First Nations Health and Wellness in Manitoba* (Allec, 2005) demonstrated variations in health status between individuals living in Northern Manitoba than those living in the southern region. Individuals in the Northern region had poorer health and shorter life expectancy than their southern counterparts. This finding could be attributed to Northern residents having lower healthcare utilization rates, which is in keeping with what is known; healthcare specialists were more difficult to access given the geographical location (Pachkowski, Moss, Racher & Annis, 2009).

In addition, geographical location is also compounded by jurisdictional ambiguity regarding the federal and provincial governments' respective roles and responsibilities concerning First Nations people (Pachkowski et al., 2009). The jurisdictional issues impact access to health care for Northern communities in Manitoba (Pachkowski et al., 2009).

Issues and problems on access to care based on geographical location are not unique to Canada. A study in New South Wales, Australia by Mitsch, Curtin & Badge (2014) used semi-structured interviews to investigate brain injury rehabilitation services' equity to rural and remote areas. The sample consists of fifty-nine (59) service providers from thirty-five (35) organizations, six (6) people with ABI and seven (7) family members. The study reported that

distances between where services are and ABI survivors' residence (remote areas) resulted in reduced access for service providers and service users. For those living in remote areas, service availability and service intensity are compromised. This affects the rapport built between service providers and service users, including their families, coordinating the support (Mitsch et al., 2014).

Moreover, the authors postulate that Aboriginal people residing in rural and remote areas of Australia find it challenging to access rehabilitation services post-ABI (Mitsch et al., 2014). The study proposes that services for Aboriginal people residing in rural and remote areas in NSW, Australia, require innovative alternative models that address culturally relevant needs. Methodologically, Mitsch et al. (2014) study employed an exploratory and descriptive approach guided by a steering committee of 12 members representing managers of allied health organizations. Although the study contained a clear statement of the study's aim, it did not justify its design.

Geographical location can be a barrier to rural residents' needs being met, and their access to care is often not met. They often face hurdles when seeking health care, especially with access to information, transportation, and the availability of ABI specialists and services being the most acute unmet needs (Solovieva and Walls, 2014). The Solovieva and Walls (2014) study surveyed n= 722 consumers obtained from the TBI registry in West Virginia. The rural area respondents revealed that the top barriers they found to accessing services were (1) 36% lack of knowledge of available services and resources, (2) 33% cost of services, (3) 33% difficulty navigating the system, (4) 28% difficulty finding qualified providers who have TBI expertise and (5) 28% proximity of services. These results are consistent with Schootman, Buchman & Lawrence (2003), who analyzed the demographic characteristics and types of services received among seventy-eight (78) individuals with TBI in Missouri, USA. The study compared consumers with TBI from rural (28 counties) and urban (50 counties). The study results indicated that rural and urban TBI survivors generally have the same demographic characteristics, injury severity, and neuropsychological abilities. However, urban consumers have better vocational and rehabilitation outcomes than rural consumers (Schootman et al., 2003).

Along with location as a barrier comes the issue of transportation. Transportation has ramifications for health care access among rural residents. Without adequate transportation,

delays in receiving care occur, leading to a lack of proper and consistent treatment. In northern regions in Manitoba, issues related to distance and transportation affect access to care. Some remote communities depend on air and rail travel or winter ice roads (Pachkowski et al., 2009). At the same time, travel to Winnipeg for specialized services is not only complicated by distance, but it is also expensive and time-consuming (Pachkowski et al., 2009).

A breadth of research suggests that poor communication and lack of knowledge from healthcare providers may affect a specific disability group, such as brain injury survivors and their interaction with the healthcare system. Addressing this notion of provider-specific barriers such as provider-client relationship, Dams-O' Connor, Landau, Hoffman & De Lore (2018) conducted seven (7) focus groups among brain injury survivors (n= 44) across Seattle, Washington and New York. Their study has shown that loss of trust and confidence in a given provider and the belief that the provider could not address patients' health concerns were cited as reasons for not consuming medical treatment. Moreover, this study revealed that physicians demonstrated a lack of knowledge about ABI led to survivors feeling that their health problems were not understood (Dams-O'Connor et al., 2018). Although the study had a small sample size, coupled with a wide range of time since the injury occurred, data was gathered from brain injury survivors. Responses from all seven focus groups were consistent. However, the open and more interactive nature of the method used may have influenced participants' degree of disclosure, thus giving responses in agreement with others' ideas.

Literature found that patients treated by their providers with respect and dignity reported highly satisfied with services (Napoles et al., 2009; Saha et al., 2003). Interpersonal relationships and trust towards service providers affect service satisfaction (Lewis et al., 2002). Moreover, Redpath et al. (2009) study revealed that building trust and relationships are affected by service providers' prejudicial attitudes.

Access to care is also affected by stigma. Weiss, Ramakrishna, & Somma (2006) posit that stigma is a pertinent public health issue as individuals who experience stigma are less likely to utilize and receive health and social services. As experienced by ABI survivors, disease-related stigma puts the individuals at risk for worsening conditions, negatively affecting their recovery (Link & Phelan, 2006).

Redpath et al. (2009) investigated healthcare professionals' attitudes towards individuals with TBI using a sample of 460 health care providers. The study showed that ABI survivors

whose brain injury was their fault received higher prejudicial evaluations than those who were seen as ‘blameless’ by qualified health care providers instead of those still in training. Additionally, this suggests that negative attitudes exist towards survivors of brain injury among qualified healthcare professionals, which may lead to a display of adverse behaviour towards the latter (Redpath et al., 2009). Acquired brain injuries that were perceived to be caused by the individuals might trigger prejudicial attitudes and hostile behaviour towards survivors within the healthcare system post-injury, which may serve as potential stigmatization routes (Redpath et al., 2009). The role of stigma in access to care warrants consideration. It could lead health care providers to be less willing to allocate valuable time, resources, and energy resulting in inequity in accessing care (Redpath et al., 2009).

A study by Poritz et al. (2019) posit that brain injury survivors may experience perceived stigma in the form of negative attitudes or discriminatory behaviour. Compared to social or public stigma, perceived stigma refers to the internal experience of stigma by an individual with a disability (Poritz et al., 2019). A sample of 504 ABI survivors from three different facilities revealed post-injury affective factors such as depression and anxiety are associated with perceived stigma, which affects an individual’s community participation. These findings are relevant primarily to treatment and rehabilitation goals, where increased participation is needed. The study suggests that service providers should consider the role that perceived stigma plays in addressing psychological and behavioural issues common after brain injury.

In summary, the studies reviewed seemed to favour a link between contextual factors such as the insurance, geographic location, transportation, prejudicial and/or attitudinal barriers and accessing health and social services.

### **Individual Characteristics**

Several studies have reported injury severity as a predictor of health care utilization (Willemse-von Son et al., 2009, Hodgkinson et al., 2000, Vangel et al., 2005; High Jr. et al., 1995). Turner and Stokes (2005) suggest that a coordinated team most effectively delivers rehabilitation of moderate to severe injury of professionals from relevant disciplines. A recent Canadian study by Chen et al. (2012) demonstrates that inpatient rehabilitation or institutionalized care is mostly associated with need factors such as the severity of the injury as measured by the length of stay (LOS) in the hospital. Utilizing the variables based on the

Andersen Behavioural Model framework, inpatient data from the years 2003 to, and including 2007 from Ontario's Discharge Abstract Database (DAD) were used to examine factors associated with discharge destination following an acquired brain injury. Given that the study used administrative data, findings may have suffered misclassification bias using ICD-10 coding in selecting samples regardless of severity or whether brain injury is the responsible diagnosis category. The discharge destination is also affected by family and caregivers' availability; which administrative data could not supply.

Furthermore, Ta'eed et al. (2011) tested this hypothesis by investigating factors associated with service utilization among 175 mTBI survivors. Data from the study showed that increased service intensity, or the total number of disciplines to which the patient was referred, was associated with greater injury severity. Moreover, the Ta'eed et al. (2011) study revealed that referral to assist with physical deficits such as occupational and physical therapy was associated with more severe injuries. However, it is essential to note that these results were based on a population-based study in a geographically distinct location on the island of Tasmania in Australia. The results may not be generalizable to other regions with more than one facility like Manitoba.

A prospective follow-up study among 504 adults with severe TBI identified the injury's severity as a primary predictor of service utilization (Jourdan et al., 2015). Investigators found that priority was given to services addressing physical impairments such as physiotherapy and speech therapy than services associated with activities and participation. Conversely, therapy for cognitive impairments was inadequately addressed even though it is one of the main areas of concern in brain injury care (Jourdan et al., 2015). While the study illustrated the need for service on cognitive impairments, only severe TBI survivors were included. This may affect the generalizability of results when applied to individuals with mild forms of brain injury. Also, the study's geographical setting was predominantly urban, which includes a broad range of social environments that could yield different findings in a less urban area in Manitoba.

Another individual characteristic with a breadth of supporting literature is gender differences. Several research studies have shown gender differences in accessing and using services, with women more likely than men to seek and use health and social services. Women were generally more likely to seek health care and mental health care than men (Drapeau,



Lesage, & Boyer, 2005). A study in British Columbia, Canada, found that females have a higher rate of unmet health care needs (Socias, Koehoorn & Shoveller, 2016).

[There is no unified theory that exists explaining these gender differences. Scientists have offered numerous hypotheses, such as those that pertain to differences based on biological needs and issues between sexes to differences in social and psychological needs. Girls and women worldwide sustain approximately one-third of traumatic brain injuries (Toor et al., 2016). Studies suggest that their gender does not affect outcomes in the setting of acute and chronic brain injury (Coimbra et al., 2003; Farace et al., 2000). On the contrary, compared with men, women with a brain injury are more likely to report emotional and cognitive issues, experience a considerable risk of abuse, and loss of emotional and financial support (Toor et al., 2016).

In a study among Canadian women with TBI (W-TBI), Toor et al. (2016) found that women are twice more likely to visit a family physician than men with a TBI and five times as likely to use community-based health care services than women without a TBI. In addition, the study suggested that w-TBI reported higher satisfaction with care and the perceived quality of access to care. Toor et al. (2016) also posit that the gender inequities inherently built into the labour marketplace put women at a disadvantage when receiving disability benefits; as benefits are proportionate to income, and receiving less income also means lower disability benefits for women with TBI (Toor et al., 2016).

Despite awareness of the diverse experiences of brain injury between men and women (Alston & Jones, 2012; Sample and Darragh, 1998), there is still limited research on the implications of those differences. Using a qualitative pilot study with sixteen (16) participants, Haag et al. (2016) explored gendered ramifications of internal and external resources available for women with a TBI from survivors' and caregivers' perspectives. Findings revealed that the social construction of gender contributes to women's experiences living with a TBI, which impacts their access to care (Haag et al., 2016). According to Haag et al. (2016), gender roles appropriated to women, such as mothering/caregiving, may exacerbate the struggle of living with an acquired brain injury. Further to this, change in employment status is common post-injury, owing to the consequences of living with an ABI. Confronted with gender-related issues due to lack of pay equity coupled with existing systemic and structural concerns, women appear to be at a disadvantage when returning to work. While this study's results are relevant to

women with brain injuries, the small sample of mostly mature women from across Canada lacks a diversity of race, ethnicity, sexual orientation, age, and gender identities.

Among US veterans, gender was a significant predictor of outpatient services following a brain injury (Cogan et al., 2019). Further, Cogan et al. (2019) found that female veterans with mTBI reported more neurobehavioural symptoms than male veterans. A retrospective database study of 12,144 veterans diagnosed with TBI indicated that men with mild TBI had lower outpatient utilization than women but had more inpatient utilization than the women with TBI (Rogers, Smith, Weaver, & Ganesh, 2014).

A qualitative study conducted by Sample & Darragh (1998) with twenty-one women with ABI from rural and urban areas found that they experienced issues obtaining an ABI diagnosis, receiving misdiagnoses, and experiencing marginalization from having sustained an ABI. These reported issues subsequently affect accessing care, including problems with service providers and service systems. An improved understanding and recognition of brain injury symptoms could make for better diagnosis and, therefore, a timelier and effective intervention (Sample and Darragh, 1998). Data from the study revealed that urban and rural women's experiences were similar except that urban women had more financial issues associated with living in an urban area. This study suggests that while no two brain injuries are alike, there may be common challenges experienced by women with disabilities. Sample & Darragh (1998) cautioned about the study's potentially limited generalizability due to the lack of corroboration of information. Conversely, the study could not isolate the findings solely on women experiencing brain injury or women accessing health care in general.

Age is another predisposing individual characteristic associated with access to care. With increasing age, evidence suggests that age affects the trajectory of recovery (ERABI, 2019). Swaine et al. (2016) investigated service providers' perceptions of referral and admission criteria to brain injury inpatient rehabilitation in two of the most populated Canadian provinces: Quebec and Ontario. The researchers used a cross-sectional referral/admission web-based survey to investigate healthcare providers' perceptions (n=345) on their referral and inpatient rehabilitation admission decision-making. The study revealed a striking discrepancy in how health care providers perceived rehabilitation potential. However, older age and the combined presence of cognitive and behavioural deficits were consistently associated with significant decreases in the likelihood of referral or admission to inpatient rehabilitation (Swaine et al., 2016). Although

Swaine et al. (2016) used a large sample, the results were based on the health provider's perceptions and not observed behaviour. The survey instrument used in this study also did not undergo reliability testing or extensive validation. Other than age, patient-related and organizational factors could affect referral decisions but were not investigated in the study.

Conversely, another study supports the role of age in access to care. Consistent with Swaine et al.'s (2016) findings, Djikers et al. (2013) found that older ABI survivors received fewer therapy per day and shorter length of stay in acute care and rehabilitation than younger ABI survivors.

While age is not a criterion for decisions on post-hospital referral, results from the study conducted by Foster, Tilse & Fleming (2004) highlighted preferential treatment for younger ABI survivors for referral and admission to rehabilitation centres, believed to fare better in recovery than those who are older. Utilizing a combination of observations of team meetings (n=10) and semi-structured interviews (n=18 practitioners), findings revealed that decision-making on the referral process was generally shaped by patient factors such as recovery potential and age. On the other hand, a study in Australia among 175 mTBI patients lends support to age as a factor in referral to physiotherapy (Ta'eed et al., 2011).

Research has pointed to disparities in health care service utilization based on ethnicity in both the United States and Canada (Lasser et al. 2006). Bias in health care among ethnic groups has also been hypothesized. A participatory research study in Canada (Keightley, 2009) with a purposive sample of fourteen (n=14) practitioners using in-depth interviews was conducted to explore health care practitioners' experiences working with Aboriginal clients with ABI. Findings from a framework analysis suggest a need for a specialized category for Aboriginal clients recovering from ABI. As defined in Ontario, ABI does not include brain damage from solvent abuse and hanging, which appears to be a more significant concern among Aboriginal communities. Besides, concurrent mental health disorders and substance dependency may interfere with admission to brain injury programmes. Health Canada (2011) found that Aboriginal and First Nations populations have higher than average substance abuse rates and mental health disorders. Keightley et al. (2009) hypothesized that ethnic status might be correlated with ABI factors such as poverty, living in dangerous or unsafe conditions and restricted opportunities. These factors increase the individual's susceptibility to traumatic events, injuring their brain and influencing one's likelihood of seeking treatment. Furthermore,

the study suggests that while there are issues of stigma and social isolation among the brain injury population and minority status, it is also associated with limited access during recovery (Keightley, 2009). Ethnic disparities in functional outcomes could result from differential access to diagnosis and treatment (Knightley et al., 2009).

### Studies on Experiences of Accessing Care

ABI survivors have the same health needs as every other member of the population. Yet, experiences of access to care may be complicated due to impairment and long-term disabilities. Contextual factors, individual characteristics and health behaviours can directly or indirectly affect health outcomes.

Table 3

#### *Research Studies on ABI Experience of Access to Care*

| <b>Author/Year/<br/>Region</b>          | <b>Purpose</b>  | <b>Findings</b>   | <b>Theme</b>                      |
|---|---|---|-----------------------------------|
| Braaf et al.<br>(2019)<br><br>Australia | To explore experiences of care coordination during the first four years after severe traumatic brain injury<br><br>Design: a qualitative longitudinal cohort study<br><br>N: 12 (6 ABI survivors, six family members) | The study findings revealed that severe TBI survivors experienced ineffective care coordination due to a lack of a crucial person coordinator leading to difficulty accessing services.   | Case management/care coordination |
| Eliacin, J., et al. (2018)<br><br>USA   | To understand the ABI survivor's and caregivers' lived experiences and inform ABI's healthcare delivery policies and practices.<br><br>Design: Qualitative study  | Findings show that ABI survivors experience unmet needs due to the following barriers in accessing care (1) access to outpatient treatment, (2) availability of services, (3) age-appropriate health services, and (4) acceptability of services. | Barriers to access to care        |

|                                     |  |  |                                 |
|-------------------------------------|--|--|---------------------------------|
|                                     | N: 62 ( 34 ABI survivors and 28 caregivers)  |  |                                 |
| Leith, K. et al.<br>(2004)<br>USA   | <p>To explore TBI survivors' lived experiences in accessing care and learn more about the service delivery system's existing gaps.</p> <p>Design: Qualitative using focus group</p> <p>N= 24 (across four focus groups with 6 participants each)</p>   | Findings of the study show that survivors and family caregivers found the existing service delivery system as unorganized, uneducated, unresponsive and uncaring.  | Outcome factors:<br>Unmet needs |
| Lefebvre et al.<br>(2005)<br>Canada | <p>To investigate ABI survivors' experiences, their family caregivers, and the service providers involved in the continuum of care. Moreover, the physicians and health professionals involved, from the critical care episodes and subsequent rehabilitation.</p> <p>Design: Qualitative design</p> <p>N= 53 (8 survivors, 14 caregivers, and 22 healthcare provider)</p> | Results revealed the difficulties encountered in accessing care in all phases of the recovery. The study lack of material and professional resources constitutes a barrier to accessibility of services for the person with TBI. | Outcome factors                 |

|   |   |  |  |
|---|---|--|--|
| McDermott, G. & McDonnell, A. (2014)<br><br>Ireland | To explore the experiences and perceptions of family caregivers and ABI service providers working in Ireland.<br><br>Design: Qualitative, exploratory design using focus groups.<br><br>N= 18                                     | Findings revealed the need for systemic change in Irish brain injury service delivery and developed a better partnership with primary stakeholders to improve ABI survivors' outcomes.   | Health behaviours<br>Family involvement, patient perspective |
| Munce et al. (2014)<br><br>Canada                   | To conduct a systems analysis on community and health services for ABI survivors in Ontario<br><br>Design: Triangulation design<br><br>N= 42 healthcare professionals   | Findings revealed the significant issues that need to be addressed to improve services for the ABI population. Specifically, the study reported (1) a lack of services for children/adolescents, (2) service gaps for individuals with co-existing mental health conditions, (3) a lack of employment services; (. | Health behaviours  |
| O'Callaghan, A., et al. (2010)<br><br>Australia     | To investigate the continuum of care experienced by adults and their significant others following a moderate to severe traumatic brain injury (TBI) in Victoria, Australia<br><br>Design: Quantitative using survey<br><br>N= 202 | Participants reported being able to access acute, inpatient and outpatient services. However, participants revealed a limited involvement in access to care  | Outcome factors  |

|   |  |   |                 |
|---|--|---|-----------------|
| Picenna et al.<br>(2016)<br><br>Australia | To describe and synthesize the perspectives of patients with ABI and their family/ caregivers on the transition from hospital to home to better understand opportunities to optimize the process<br><br>Design: Qualitative review<br><br>N= 5 databases | The study revealed poor communication, limited survivors/caregiver engagement, and disorganized support services contributed to the unsatisfactory reintegration to home and community. | Outcome factors |
|---|--|---|-----------------|

Examining ABI survivors' experiences regarding access to care is essential to understanding their behaviour towards using services. This section will review care experiences that typically focused on the patient and her/his caregiver's experiences. Looking at this will lead to a better understanding of the long-term healthcare needs of survivors.

There are few Canadian studies on the perspective of ABI survivors on care experiences. A study in Montreal investigated the experiences of ABI survivors, their family caregivers, and the service providers involved in their care (Lefebvre et al., 2005). The semi-structured interviews (TBI n= 8, families n=8, and service providers n=9) found that access to services during critical care and rehabilitation is adequate from the service users' perspective. However, upon discharge from the hospital, ABI survivors and families found that there are gaps in terms of community- based resources. Although the service providers' perspectives in terms of access and availability of care and services are similar to the service users, the former is more critical of the system in place, making it hard to access services. Lefebvre et al. (2005) study revealed that the health and social services need to develop resources addressing accommodation, social integration services, neuropsychiatric, and medical services in partnership with ABI survivors and their family caregivers. Although this study has a small sample, its credibility was ensured by assessing inter-rater reliability throughout the coding and analysis process. This study also has

strong transferability to the Manitoba setting, given the similar health care context in ABI service delivery in Quebec and Manitoba.

In Ontario, Munce, Laan, Vander, Levy, Parsons & Jaglal (2014) conducted a systems analysis of community and health services for acquired brain injury survivors. The study revealed a lack of services for “children/adolescents across the province and the continuum of care, service gaps for individuals with co-existing mental health conditions, lack of services related to employment, and a need for more organizations to track patients’ outcomes” (p. 1049). The community and health services for ABI in Ontario demonstrated gaps in counselling, neuropsychological and/or psychiatric services among community-based organizations (Munce et al., 2014). Furthermore, the study also reported fewer organizations with general psychiatrists, neuropsychiatrists, clinical psychologists, and neuropsychologists despite the significant occurrence/co-existence of mental health needs among ABI survivors.

Eliacin et al. (2018) conducted a study in the United States to examine patient and caregiver experiences of health services for moderate to severe TBI survivors in Indiana (n=62). The qualitative study revealed that participants experienced inadequate service delivery due to inadequate access to outpatient services, unavailability of specialized services, lack of age-appropriate and long-term health services, and barriers to transportation that limited their access to care. These findings were consistent with Leith et al.’s (2004) study conducted among four focus groups with TBI and their families living in South Carolina (n=21). Further, the study reported that the existing TBI services were highly fragmented, presenting barriers to access and healthcare utilization.

In addition, health care providers and the general public displayed a lack of awareness and knowledge about brain injury. The small selected sample had used services at least once prior to the study, which may have impacted their perception of the services. Despite these results, the experiences with received services may have been a function of selection bias, which may not be generalizable to other locations such as Canada, particularly Manitoba.

Need for care refers to the illness or condition variable in the behavioural model, which includes the individual’s report of symptoms and illness (perceived need) and service provider’s diagnostic evaluations of illnesses and symptoms (evaluated need). Studies of ABI populations found that evaluated needs, such as the severity of the injury and physical and cognitive disability, were factors that affected health care utilization among brain injury survivors



(Hodgkinson et al., 2000; High Jr. et al., 1995; Vangel et al., 2005). According to Andersen (2008), the perceived need is vital to understanding the care-seeking process and adherence to medical regimens. Among brain injury survivors and caregivers, service providers do not often meet perceived needs. Unmet perceived needs appeared to be associated with behavioural and psychosocial outcomes such as employment and mental health services by brain injury survivors (Corrigan, Whiteneck & Mellick, 2004). Unmet need for healthcare is a construct that is distinct from equity. Healthcare professionals may evaluate unmet healthcare needs as the absence or inadequate use of health services deemed necessary for a particular health problem.

Another study in Illinois, USA, found that brain injury survivors with more significant unmet needs tended to receive fewer services and reported lower medical health and well-being (Heinemann, Sokol, Garvin & Bode, 2002). Furthermore, the study provided more evidence of the high prevalence of unmet emotional, cognitive, and social needs among ABI survivors with less apparent physical impairment (Heinemann et al., 2002).

Health professionals and service providers often hold a significant role in making decisions for ABI survivors. Therefore, their perspectives and interpretations will determine ABI survivors' access to services (Leith et al., 2005). These decisions need to be responsive to the needs of the ABI population. Thorough knowledge of ABI and its medical and psychosocial consequences is needed when making these decisions. However, research studies point to a lack of adequate and accurate knowledge about ABI among service providers who work with ABI survivors and their families (Swift & Wilson, 2001, Lefebvre et al., 2005). Results revealed that brain injury survivors, families/caregivers, and healthcare providers found that access to information, uncertainty experienced by all service providers in the care process, relationships between patients and service providers, continuity of care and services, and the adaptation process of the ABI survivors and their families were the themes characterizing barriers to health and social services (LeFebvre et al., 2005). Similarly, participants believed that the lack of information and resources exhausted the health professionals, which compromised service delivery and care coordination.

Consistent with Lefebvre et al.'s (2005) study, Muus et al. (2006) found that the scarcity of ABI-trained service providers and advocates, lack of centralized source of information on available services, inadequate source of funding, and lack of individualized treatments were cited as major barriers to access to care.

In a similar vein, the Medical Research Institute of New Zealand (McNaughton & Wadsworth, 2000) identified a lack of knowledge among brain injury service providers, which, in turn, affects treatments which leads to fragmented care coordination, poor access to services, high turnover of case managers, and focus on physical injuries rather than cognitive, emotional and psychological issues (McNaughton & Wadsworth, 2000).

The continuum of care following ABI often involves providing post-acute care services for survivors and their families (Degeneffe, Green & Jones, 2016). A two-pronged data collection that resulted in 22 completed surveys among n=168 families in the southwestern part of the US revealed that a lack of communication on the range of available supports for brain injury survivors is attributed to not knowing the services were available, thus preventing access to services by those who needed them. Based on these findings, Degeneffe et al. (2016) suggest that professionals and providers need to be diligent in informing survivors and families about available services when discharged. Strategies should be developed to better link survivors to available outpatient and community-based services.

The patient perspective and family involvement in the provision of care were highlighted by McDermott & McDonnell (2014). A qualitative study with a sample size of 21 survivors and caregivers found evidence for the need to involve the family and make information related to brain injury more available and accessible. The findings of Picenna et al. support results from this study. (2016) who used electronic databases to describe and synthesize the perspectives of patients with ABI. Family engagement and support are two major themes that were identified as factors contributing to the quality of and satisfaction with care for the ABI population (Picenna et al., 2016).

### **Summary**

Studies on access to care from brain injury survivors' perspectives are scant, but the number is growing. Access to care was used as synonymous with service utilization in the research that was reviewed. A significant body of literature reveals the health system's contextual aspects, such as location, transportation, and policies, influence access to care for ABI survivors. However, studies have concentrated on in-patient ABI survivors using administrative data. Not many were undertaken on their non-hospitalized and community-dwelling counterparts.

The majority of the literature cited in this chapter was quantitative. However, for studies that utilized qualitative methods, care experience was studied mostly from the caregivers' perspective rather than the affected ABI survivors themselves. In the case of non-Canadian based research, generalizability should be assessed with caution, especially for countries without universal healthcare systems such as the United States. According to Mayberry et al. (1999), the social insurance type of Canada's healthcare is based on fairness. It operates from different principles than those of private insurance principles of actuarial fairness.

The literature also described a unique disability experience for ABI survivors. A cognitive yet often-invisible impairment affects the ABI survivors' positioning in the disability world and recognizes their perceived, unmet needs.

The breadth of the studies reviewed was from countries with universal healthcare coverage, such as Australia, New Zealand, and the Netherlands. No studies could be found that are directly related to brain injury and conducted in Manitoba. However, there is likely good generalizability to Manitoba of studies conducted in Canada.

These observations of the literature point to an intersection between disability, contextual factors, and ABI survivors' access to care. Thus, these key points will be considered in understanding how and why research participants characterize aspects of their access to care.

## **Theoretical Framework**

Andersen's theory has been generally used in literature based on the current knowledge of healthcare and service utilization. While Andersen's behavioural model is comprehensive and robust, it was not developed for people with a disability, explicitly using the ABI population's perspective. On the other hand, critical disability theory provides an avenue to rethink what we know about disability. It deals with understanding the relations of power, language, and knowledge inherent in establishing ways to respond to people with disabilities (Shakespeare, 2002; Meekosha and Shuttleworth, 2009).

This section will introduce key aspects of Andersen's Behavioural Model (Andersen, 2008) and align them with the critical disability lens to construct a novel conceptual approach for explaining differential access to care. Andersen's Behavioural Model and critical disability theory will be described in turn. Then I will explain my combination of Andersen's model and

the critical disability studies framework into a conceptual framework that constituted the rationale for my research design and methodological choices.

### **Andersen Behavioural Model of Health Care Use**

The Andersen model was initially formulated to assess health services' quality and efficacy to improve health systems (Andersen & Aday, 1974). The model has undergone several revisions, and the current version is the sixth iteration from the model devised in 1974. The current Andersen model (Andersen, 2008) is the most comprehensive model to date and includes factors such as contextual characteristics and service provider-client interactions, which were not present with the previous versions (Andersen, 2008). In the original model, Andersen (1974) focused more on individual and family level characteristics such as demographic information, family's social structure, and health beliefs; enabling resources such as family and social factors; and need factors such as perceived and evaluated needs.

The initial model theorized that predisposing characteristics influenced enabling resources, which in turn influenced need. Goldsmith (2007) argued that the study of health access has evolved to include the influences of the individual and the healthcare system, and the social environment.

The changes in today's healthcare system, especially the growth of managed care on health access, have changed the model. The latest iteration involves a broader understanding of the effects of this change. Andersen's (2008) Behavioural Model of Health Care Use (Figure 2) incorporates micro and macro-level influences in the model. The original components, such as predisposing characteristics, enabling resources, and need, are still present. However, the current model divides the factors into four broad categories. Andersen (Andersen & Davidson, 2008) defines access as "actual use of personal health services and everything that facilitates or impedes their use. It is the link between health services systems and the populations they serve. The authors further posit that access refers to the utilization of services and to get the right services at the right time (p. 3). The first domain consists of contextual characteristics or the circumstance and environment of healthcare access. This domain includes (1) predisposing variables such as social beliefs and demographic factors, (2) enabling variables such as health policies and financing, and (3) need variables such as population health indices and environmental characteristics (Andersen, 2008). This domain investigates organizational factors that influence individual health and healthcare utilization.

The second domain falls under individual characteristics and consists of factors such as demographic information, social factors and personal beliefs (predisposing); personal and family finances (enabling), and perceived/evaluated health (need). These variables are also influenced by contextual characteristics and an individual's health behaviours and health care outcomes.

Another domain of the Andersen model is called health behaviours. This includes the following factors (1) personal health practice, which refers to the individual's health habits that influence his/her health status, (2) process of medical care, which refers to the provider's behaviour that affects access to care and (3) use of personal health services, which is the essential component of health behaviours (Andersen & Davidson, 2008, p. 8). According to Andersen (2008), health behaviours are subject to outcome variables. Outcome variables are associated with an individual's experience in accessing care, which includes evaluated health and an individual's satisfaction with his or her experience of the system. The outcome variables refer to the result of health behaviour and contextual and individual characteristics as shown through (1) perceived health status or the extent to which the person can live a functional, comfortable, pain-free existence; (2) evaluated health status as indicated by professional health standards such as patient functioning and physiology and (3) consumer satisfaction or how individuals feel about the health care they receive.

Figure 2. Andersen's Behavioural Model of Care

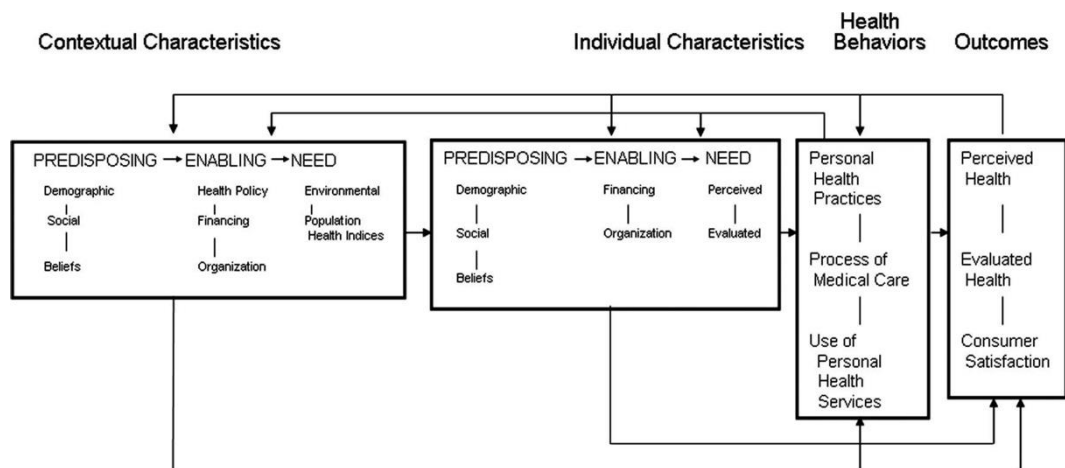


Figure 2. Andersen's Behavioural Model of Healthcare Utilization. Reprinted from "National Health Surveys and the Behavioral Model of Health Services" by R.M. Andersen, 2008, *Medical Care* 46(7), 647-653. Copyright 2020 by Wolters Kluwer Health Inc. Reprinted with permission.

Pathways in the model represent multiple influences on health behaviours and outcomes. The domains and their components are interrelated. For example, health policy changes may directly affect the delivery system's characteristics, such as physicians' and services' availability in a geographic area. These changes may, in turn, affect utilization patterns and, consequently, consumer satisfaction (Andersen, 2008).

Although Andersen's model (Andersen, 2008) is an excellent way to frame access to care, this theory does not fully explain people's experiences of social injustice, power and privilege inherent in the expert-driven, dominant culture of health care. To critically analyze these experiences, I will incorporate Critical Disability Theory to illuminate further systemic issues and structural barriers to accessing care.

### **Critical Disability Theory**

Michael Oliver said that "human beings give meaning to objects in the social world and subsequently orient their behaviour towards these objects in terms of the meanings given to them" (1990, p.3). Therefore, if a "disability is defined as social oppression, it may be translated into social and economic policies that will meet people with disabilities' needs as victims of societal and systemic barriers" (Oliver, 1990, p. 33).

Disability literature presents many ways of understanding disability. However, two broad definitions are paramount in explaining disability discourses. |According to Meade (2014), "models of disability have increasingly recognized the role of contextual factors and have explicitly incorporated contingencies in the pathways between pathology and disability" (Meade, 2014, p. 633).

The first definition is the medical model of disability, which approaches disability from a positivist perspective uses the standard objective measures to examine individuals and their characteristics, and how they function and defines them as having medical problems that need treatment (Hughes & Paterson, 2000). According to Oliver (1990, p.50), "medicalization of disability imposes order in the new industrial society and describes the way in which medicine became the main agent in this process of self-control". Under the medical model, diseases and impairments are seen as consequences of some deviations from normal biological functioning. This model is also called the personal tragedy theory of disability, positing that disability is a natural disadvantage suffered by disabled individuals when placed in competitive social situations (Hirandani, 2011). This model of disability disempowers people with disabilities and

neglects societal issues, such as exclusion, the policy environment, and the social setting. As a result, the medical model has medicalization as a critical aspect (Oliver, 1990). It focuses on individual conditions and little attempt to integrate the social, economic, and physical barriers for people with disabilities.

The social model of disability emerged to challenge the medical understanding of disability and consider historical and cultural contingencies (Hughes, 2000). Disability, according to the social model, encompasses all factors that impose restrictions on people with disabilities. These restrictions take the form of negative social attitudes to institutional discrimination, from inaccessible public buildings to unusable transportation systems, from segregated education to exclusion and so on (Hirandani, 2011). As Oliver (1990) explained, impairment is not the cause of social exclusion, but the way people responded to people with impairments is the cause. The social model differentiates impairment as physical characteristics such as a body part that is missing or defective or malfunctioning and disability as a set of disadvantages that impaired people experience due to a social orientation towards the normal category (Shakespeare, 2000; Oliver, 1990). While impairment, pains and struggles cannot be eliminated, disability is understood as a form of social oppression generated by barriers, (dis)ableism and exclusion from social life (Oliver & Barnes, 2012).

#### *Critical Disability Studies (CDS)*

Critical disability studies cover critical theoretical developments (Berghs et al., 2016). Critical social theory as a framework does not see society as a well-functioning organism (Alderson, 1998). However, it sees society as “a collection of many factions competing for power and resources” (Alderson, 1998, p. 1203). The critical social theory assumes that cultural, political, and economic circumstances are not natural and fixed; instead, they are created and constructed (Savage, 2016). Power, structures, and knowledge construction are relevant constructs in understanding health utilization and health equity (Princeton, 2015; Alderson, 1998; Scrambler, 2002).

Critical disability theory posits that “disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; instead, it is a question of politics and power (lessness), power over, and power to” (Devlin & Pothier, 2006, p.2). Further, CDS questions the dualism of impairment and disability. Meekosha and Shuttleworth (2009) argue that critical disability studies go beyond the paradigm of the social model of

disability, that it should be eclectic and guided by unique interdisciplinarity and productive debates on a range of issues and solutions (p. 65)

Rioux and Valentine (2006) contend that the medical model of disability places the primary responsibility within the person with a disability. Hence the emphasis is on cure, prevention, and rehabilitation. However, if a disability is understood as a socially created barrier, responsibility and accountability shift to the broader community (Rioux & Valentine, 2006).

Hosking (2008) characterized disability as “a complex interrelationship between impairment, individual response to impairment and the social environment” (p. 7). However, more notably, individuals with disabilities are as diverse as those without disabilities with varying backgrounds and risk factors (Meade et al., 2014).

CDS aims to frame disabled people as the ultimate intersectional subject, the universal image, the vital modality through which we can understand exclusion and resistance (Hirandani, 2011). Goodley (2011) argues that “critical disability studies start with a disability but never end with it: disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all” (p. 157). Harvey (2017) proposes that to understand brain injury survivors' lived experiences, it is crucial to recognize that ABI is not purely a social or purely a medical entity. Instead, to reconstruct the dominant medical discourses on disability, an exploration of the everyday accounts of individuals who have lived with a disability manifested through various impairments should be investigated. Harvey (2017) highlights the fluidity and complex nature of disabled people's lives. He further suggests that to enact critical disability studies “thorough, nuanced, and theoretical understanding of disability” (Goodley, 2013, p. 131), sociological theorization should be included. Meekosha & Shuttleworth (2009) argue that the exploration of disabled people's lives provides the ideal situation to initiate transformative change. This view of disability focuses on ABI survivors' accounts and their understanding of how access to care is ongoing and fluid.

A postmodernist and poststructuralist perspective, such as Foucault offered, is central to an understanding disability defined by CDS.

#### *Foucault's Governmentality, Bio-power and Disability*

Power is an essential concept in understanding access to care. Through Michel Foucault's (1978) work, his notion of power and knowledge is best understood with a discussion of



governmentality. According to Tremain (2005, p. 7), governmentality refers to the “ways of knowing and understanding how government activity is achieved and maintained and who or what can be governed, and by whom”. In Foucault's words, the government is the “conduct of conduct” (Foucault cited in Tremain, 2005, p. 7).

Governmentality is the ensemble formed by the institutions, procedures, analyses, and reflections, the calculations and tactics that allow the exercise of this particular albeit complex form of power, which has as its target population, as its principal form of knowledge, political economy, and as its essential technical means apparatuses of security. (Foucault as cited in Tremain, 2005, p. 8)

Michel Foucault's work was driven by his desire to understand the relationships of power and the nature of their intersection with social institutions and individual practices (Tremain, 2005). According to Foucault, power and knowledge are inextricably linked. The notion of power is best understood by considering knowledge production (Tremain, 2005). Foucault argued that knowledge and power are intricately intertwined “the exercise of power perpetually creates knowledge and, conversely, knowledge constantly induces effects of power” (Foucault as cited in Tremain, 2005, p. 9).

Foucault asserted that knowledge is relative; a specific view accepted could become the dominant discourse, which is subsequently held as the regime of truth (Hughes, 2005). It is produced wherever there is an institutional balance of power such that those who can exercise power with others are the ones that produce “knowledge” about those who have no access to power (Hughes, 2005). With the medicalizing of disability, people with disabilities have become a subject for the dominant professional groups, whose discourses define what it means to be disabled. The professional constructions of disability result in oppression on this population based on the construction of their disability (Hughes, 2005).

The construction and production of knowledge affect how we define, understand, and respond to disability. The social model of disability has been instrumental in rendering people with disabilities “experts” concerning their conditions (Hughes, 2005). The categories and concepts that we use, who, where, and how we come to understand “disability” are specific to the individual's culture and history (Yong, 2007). A Foucauldian perspective on disability recognizes the powerful role that language and symbolism play in constructing disabled identities and the disability population (Hughes, 2005). The conception of power and its linkage to the body offers a way to explain the practices of subjectification that have variously

separated, institutionalized, and normalized disabled people (Hughes, 2005, p. 82). In other words, Foucault argues that disability is a product of modernist bio-power or the effect of the medical management of people with impairments (Hughes, 2005).

Therefore, bio-power is the power redirected to invest in life to discipline both individuals and populations (Tremain, 2005). This form of power operates by merging both the administration of individual bodies and the large-scale everyday living (Tremain, 2005). Foucault pinpoints that the beginning of modern biomedicine paved the way for distinguishing between the normal and pathological. Such a distinction sustains “disability as a form of power that both contribute to the formation of identity and establishes impairment as its necessary and sufficient condition” (Hughes, 2005, p. 81). According to Tremain (2005), Foucault's concept of bio-power is relevant in analyzing disability. Foucault argued that “practices of division, classification, and ordering around a norm had become the primary means by which to individualize people, who come to be understood scientifically, and who even come to understand themselves in this mode” (Foucault as cited in Tremain, 2005, p. 6). Indeed, “the power of the modern state to produce an ever-expanding and increasingly totalizing web of social control is inextricably intertwined with, and dependent upon, its capacity to generate an increasing specification of individuality in this way” (Tremain, 2005, p. 21).

Hughes (2005) suggests that bio-power's capacity to objectivize people in this way illuminates Foucault's remarks about humans being subjects

For Foucault, to be a subject is, in one sense, to be subject to someone else by control and dependence and, in another sense, to be tied to one's own identity by a conscience or self-knowledge. Both senses of the term imply a form of power that subjugates and makes the subject (Foucault as cited in Hughes, 2005). Looking at disability through Foucault's approach means that the government treats people with disabilities as subjects to be divided and assigned meaning to (as someone impaired). This legitimizes the government's power to regulate and control people's “bodies” and their lives (Hughes, 2005).

According to Foucault (as cited in Tremain, 2005), the exercise of power creates knowledge, and knowledge frequently induces the effects of power. He further added that this knowledge had been used to exercise power over-controlling individuals (Tremain, 2005)

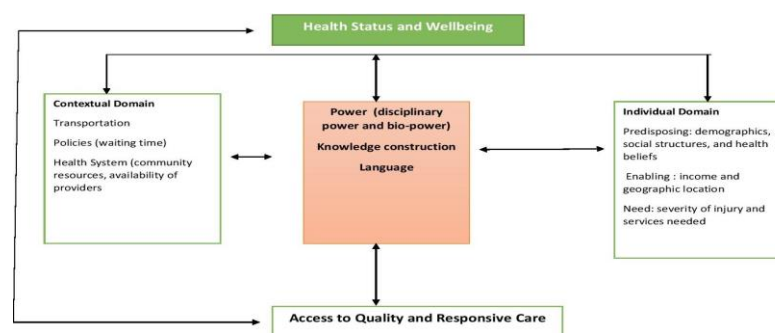
## Conceptual Framework

Utilizing concepts from Andersen's Behavioural Model of Health Care Use (Andersen, 2008) and critical disability theory, this integrated conceptual framework (Figure 3) views access to care as the dynamic interaction of contextual characteristics and individual characteristics.

Whereas Andersen's model focused extensively on factors that contribute to health behaviours and outcomes, I am interested in examining how arbitrary but deeply ingrained power, language, and alternative knowledge towards access to care and social services are. While the addition of contextual factors in Andersen's model acknowledges the environmental factors that cannot be controlled, my research is focused on examining the extent to which power, language, and knowledge produce conditions that further disadvantage the contextual and individual factors of people with disabilities, particularly those with ABI.

The figure below shows the integrated conceptual framework. As shown in Figure 3, power/knowledge and language affect the interaction between contextual factors and individual factors to influence care access. An equitable access to care Healthcare can then alter the health outcomes and the wellbeing of brain injury survivors.

*Figure 3. Conceptual Framework on Access to Care for ABI Survivors*



## Variables

Contextual characteristics are the circumstances and environment of healthcare and social services access (Andersen, 2008). In this study, contextual factors include organizational factors such as transportation, travel time, waiting time for health care, resources available within the community, and health policies.

As defined by Andersen (2008), individual characteristics are predisposing factors, enabling factors, and need factors. In this study, individual predisposing factors are defined as

characteristics of the individual pre-injury. This includes the survivor's demographics (age, gender), social structure (education, employment, ethnicity), and health beliefs (attitudes, knowledge of services/healthcare). On the other hand, individual enabling factors include geographic location, living arrangement, and income. Finally, need factors are defined as the cause of access to health and social services. In this study, need is defined as the severity of the injury and the number of services the survivor currently needs.

In this study, health services use defines health service utilization in two ways: (1) whether the individual accessed services in the past 12 months and (2) the number of times the individual used the services.

The variables, such as power and knowledge, are defined according to Foucauldian terms (Foucault as cited in Tremain, 2005). Knowledge is constructed and, therefore, not objective but rather an integral part of struggles overpowers. In this study, power and knowledge refer to service user-provider power relationships and knowledge translation/production about brain injury-related information. The service providers' interpersonal encounters will be assessed as the site where bio-powers are exercised. For instance, positioning service providers as holders of expert knowledge give them the power to recognize and respond to specific health conditions. Under Foucault's perspective on power and hierarchy, service providers maintained the upper hand as gatekeepers of services, reinforcing their dominant role in access to care. Whereas, if we position brain injury survivors as having knowledge that others cannot have, we give them the power to advocate and articulate their conditions to access care. Consequently, there is a potential to narrow the power disparity between service providers and service users.

On the other hand, the concept of language shapes how contextual factors are designed and developed, which ultimately interacts with individual factors. The language used (disability) shapes power relations and knowledge production. Thus, it continues to influence how society has and continues defining, understanding and responding to disability. Disability remains focused on the medical perspective and impairment-related factors as clinical indicators that need treatment while neglecting to address the underlying structures and processes that undermine health. For example, the recovery language used in brain injury care sits within rehabilitation and potential cure that assumes the desired return to normalcy. This model proposes that looking at brain injury within a disability-oriented epistemology and critical disability lens would alter the contextual factors and their interaction with the individual factors.

The interaction between contextual factors and individual factors influence access to care. Access to care encompasses the availability of service. Based on Andersen's model (2008), access also refers to the quality and responsiveness of services to support service users' best outcomes. To illustrate this model, ABI is a unique disability. Unlike other forms of neurological impairments such as Alzheimer's, Parkinson's, and dementia, brain injury survivors rarely suffer cognitive decline (Wilson, 2016; ERABI, 2018). Generally, ABI survivors' trajectory is one improvement, yet individuals continually experience chronic cognitive deficits that impair their ability to function (ERABI, 2018). The recognition of, and response to, the symptoms that come with living with ABI, makes access to care and service provision a critical issue. Professionals and service providers hold expertise on what constitutes an ABI diagnosis. This medical model is transposed and translated into recovery and rehabilitation programs, which further divide the inequality of power between the professional and the survivor.

This framework's central argument is the effort to bring legitimacy to ABI survivors' lived experience to authorize their condition's power and knowledge. By claiming to know, brain injury survivors become and remain the origin of knowledge through having lived the experience. To have a stake in knowledge production, survivors have the power to unsettle the dominant discourses. In this way, the development and design of contextual factors that interact with individual factors can alter access to quality and responsive care.

### **Chapter Three - Methods**

This chapter describes the research design and methods, including participant recruitment, interview procedures, data handling, and ensuring validity and credibility.

#### **Research Design**

This study explored ABI survivors' lived experiences regarding access to care in Manitoba, Canada, utilizing a critical qualitative inquiry approach based on a Foucauldian perspective that is deductive and theory or concept-driven. The data were also approached incorporating Andersen's Model of Health Behaviour (2008) to enable understanding of the experience of living with a brain injury and the effects of social, economic, and political forces on ABI survivors' access to health and social services.

The critical research design was used for this study as it was deemed appropriate to explore the power dynamics of access to care. This study's methodology was informed by the critical perspective ideology, which exposes and critiques the forms of inequality and discrimination in daily life (Denzin, 2015). According to Canella (2015: p. 140), "critical qualitative inquiry is any research that recognizes the power that seeks in its analyses to plumb the archaeology of taken for granted perspectives to understand how unjust and oppressive social conditions came to be reified as historical givens". This approach places the consciousness of social work directly in pursuit of social justice by using the lived experiences and perspectives of brain injury survivors. Denzin (2015, p. 42) posits that "the perspectives and experiences of individuals served by social services must be grasped, interpreted, and understood if solid, effective, applied programs are to be created".

Creswell (2007) states that a qualitative approach embraces the idea of multiple realities and focuses on participants' subjective meaning and experiences. The participants' perspectives and experiences in accessing health and social services will better understand the world in which they live (Creswell, 2007). This approach also allows in-depth exploration of the processes involved with ABI survivors' interaction with the healthcare and social services systems.

As a form of inquiry, critical qualitative inquiry is aimed at social and political change, which eschews any form of objectivity (Canella Perez & Pasque, 2015). This study took an activist stance, which included the commitment to use research to critique the status quo, raise

consciousness, and change the current balance of power favouring those who are powerful. This study is designed to empower the participants by building their capacity to get involved through semi-structured in-depth interviews to better understand their situations, raise consciousness, and support future action aimed at political change (Canella et al., 2015).

Critical analysis of policy and services is an appropriate means of explaining how dominance and marginalization are enacted by providing health and social services. Furthermore, ABI survivors, as individuals with a disability, belong to an oppressed and marginalized group. Postmodern, ideological, and critical research focus on the historical situatedness of the study, the importance of the research in increasing consciousness about issues of power and oppression, and—for the ideological and critical perspectives in particular—the potential of the research to create change (Guba & Lincoln as cited in Morrow, 2005).

Data were analyzed using critical change inquiry, which aims to critique existing conditions to change (Patton, 2015, p. 345). The critical change criteria are derived from critical theory, which aims to frame and engage in qualitative inquiry with an explicit agenda of elucidating power, economic, and social inequities (Patton, 2016). The goal of critical inquiry is to (1) critique and challenge, (2) to transform, and (3) to empower and change society (Patton, 2015). Using this research design provided ABI survivors with the platform to voice their lived experiences about access to care connected to power.

### **Sample and Recruitment**

This study included community-dwelling brain injury survivors who were (1) 18 years of age and older, (2) residing in Manitoba, (3) have experienced a self-reported acquired brain injury for at least two years; inclusive of traumatic, mild traumatic and non-traumatic brain injuries, (3) able to speak and understand English well enough to participate in an interview, and (4) have accessed some level of services from the health care system and/or social services over the past 12 months.

Recruitment took place through various brain injury support groups in Brandon, Selkirk, Steinbach, and West Manitoba's Brain Injury Collaborative Network. I also approached multiple organizations that advertised the study through posters and emails sent to Executive Directors and Chief Executive Officers. Interested individuals then contacted me through the contact information posted on the flyers. In addition, family doctors, psychologists, psychiatrists, social

workers, and case managers were also contacted to put up recruitment posters and flyers. Leaflets and posters were also distributed to different hospitals, care facilities, non-profit agencies such as unemployment agencies, disability service agencies, and homeless shelters in the province. The recruitment process was also aided by various government departments, such as the Department of Families and multiple regional health authorities (RHAs). In particular, the Disability Programs and Specialized Services unit of the Department of Families mailed the research poster with the study information to all program recipients diagnosed with ABI. The Southern Health Region and Northern Health region also sent information about my research to various acute care sites and medical clinics (See Appendix for memorandum of agreement and letter of approval).

Using purposive sampling, the study used the following four (4) dimensions of variation: (1) education; (2) socioeconomic status; (3) geographic location – rural/northern (outside of Winnipeg) and within the city of Winnipeg; (4) gender and (5) ethnicity (white, Indigenous populations, and visible minorities). Due to ethical considerations that come with my position at the local brain injury organization, I excluded members and service users of the MBIA because of the risk that individuals might feel obligated or coerced to participate in this study.

To capture diversity in experiences, the principles of maximum variation was used as a sampling strategy (Patton, 2016). An opportunistic and purposive approach was used. Efforts were made to sample diversity by recruiting ABI survivors from different backgrounds based on gender, education, location, ethnicity and socioeconomic status. With this strategy, no participants were excluded from the sample. However, as the study unfolds, I sought specific participants to diversify the sample. The variability of the sample was used to provide data to critically analyze the structures that may have influenced access to care and service provision.

## **Data Collection**

Data collection was conducted in two stages. First, the participants who gave their contact information were contacted over telephone or email with an information package (See Appendix C) about the research. Paterson & Scott-Findlay (2002) suggests that preparation is an essential aspect of interviewing ABI survivors. Due to common cognitive difficulties experienced after an ABI, a pre-interview was conducted to establish rapport and build



familiarity with participants' cognitive and communication deficits through discussions of routines, activities and social settings. At the same time, the pre-interview was also used to collect demographic information such as participant's age, ethnic background, relationship status (single, common law/married, separated or divorced, widowed), employment status (full-time or part-time employment, full time or part-time student, retired, retired due to disability, unemployed, volunteer/homemaker), educational level (some high school, high school graduate, college, university, graduate/post-graduate), ethnicity, income level, and employment status ( See Appendix B). Participants were also asked to answer injury-specific questions.

To optimize potential participants' understanding of the study and involve them more actively in the consent process, the consent form was read to the participants either in person or on the telephone. Information about how recordings and findings could be used and kept was provided. The participants were asked to paraphrase the consent form to gauge the participant's functional capacity, such as cognitive functioning and/or word processing abilities. This is to ensure that the participants understood the study before agreeing to participate. Participants who meet the criteria were asked to sign the form, keep one copy, and return another copy.

During the pre-interview, participants were given a choice on the interview method: (1) over the telephone or (2) in person. All participants were screened to determine their eligibility and decision-making capacity. The majority of the screening was done through telephone interviews. Two were done in person just before the main interview was conducted.

The participants who preferred an in-person interview were given a choice to select the interview setting to ensure maximum comfort and take into account the participants' tolerance of extraneous stimuli and fatigue patterns. Upon completion of the informed consent, a sixty (60) to ninety (90) minute in-depth semi-structured interview proceeded, and it was audio-recorded. Given that participants may have undergone cognitive, perceptual, and emotional changes that may have provided challenges to interviewing, two participants (2) took the option to take a 30-minute break before continuing with the interview. Thirteen participants were interviewed individually in person, with an average of 65 minutes per interview. Two participants from rural and northern Manitoba were interviewed over the telephone for geographical reasons. The telephone interviews lasted more than two hours with intermittent breaks due to interrupted wireless connections and speech issues.

A debriefing was conducted after each interview to allow participants to provide feedback about the interview process. While most participants were hopeful that their experiences would be helpful, they were also concerned about the amount of time they have to wait for the research to impact their care access. Although there was no distress raised after the interview, participants shared during the debriefing that the interview provoked some emotional responses but at the same time provided a therapeutic relief that research on accessing care is being undertaken. Participants who were interviewed over the telephone suggested that an in-person interview would have fewer interruptions and more meaningful information. Written information and resources were left with each participant and contact information should they have any additional information they forgot to interview.

### **Interview**

This study utilized an open-ended, semi-structured interview with corresponding prompts, focusing on the participant's experiences accessing brain injury services, the barriers and facilitators of accessing the services, and their perceived understanding of access to care (Appendix B). By sharing their perceptions of their own experiences in the health and social services, participants were allowed to engage in critical analysis of the institutional and systemic issues surrounding their access to services. Gregory (as cited in Paterson & Scott-Findlay, 2002, p.407) cautioned, "interview responses that seem superficial might instead reflect the injured person's unfamiliarity with the brain injury's impact on communication such as the lack of vocabulary to describe sensations and experiences".

In keeping with a critical qualitative approach, I adjusted my interview and communication style to facilitate brain injury issues. I have been working with brain injury survivors for almost a decade and have developed a level of familiarity and comfort with ABI clients. According to Paterson and Scott-Findlay (2002), active interviewing helps make sense of the challenges such as memory recall and intolerance to stimuli. Active interviewing is a form of "interpretive practice involving the respondent and interviewer as they articulate ongoing interpretive structures, resources, and interpretations" (Holstein & Gubrium, 1994, p. 121). I endeavoured to create a safe environment for the participants. However, I was also cautious in analyzing the interview's words and language. I had included participants with speech issues to be inclusive of those whose voices are often not heard. Although I found a way for one participant with aphasia to express his opinion by writing some of his answers, one participant

was too frustrated to continue or try the interview again. Consequently, participants were able to express their perspectives and have their voices heard.

In-depth interviews generate narratives and understandings of the participant's experience and its meaning for the study domains (Denzin & Lincoln, 1998). Based on the conceptual framework developed, a semi-structured interview guide was designed to explore ABI survivors' experiences accessing health and social services. The interview guide was based on an extensive literature search on healthcare access and utilization among brain injury survivors.

### **Data Analysis**

In this study, the data analysis process started with reading the first set of interview transcripts, reviewing the research objectives and reflecting on the themes, hunches and ideas that emerged from the transcription through memo-writing. The first set of interviews (three interview participants) was compared to refine my interviewing style for subsequent interviews. As suggested by Merriam (2009), data comparison informs the data collection. Further, mind maps, word clouds, cross-tabulations, maintaining memos, reformatting transcripts in NVivo Pro 12 allowed reorganization of ideas and refined the process of data analysis.

### **Data Organization**

Data from this study were stored in digital formats. Interview transcripts were saved in password-encrypted files on a personal computer. In addition, transcripts were also uploaded on a Computer Assisted/Aided Qualitative Data Analysis (CAQDAS) tool/software NVivo Pro version 12, password protected.

A thorough analysis of the data began with the process of transcription. I transcribed the entire interview data as accurately as possible. Green and Thorogood (2009) posit that transcribing an interview is an interpretive task. My transcriptions included laughter, cries, sighs, and conversation fillers to prevent my views from muddling the interpretation. Each transcript was crosschecked with all audio recordings to ensure accuracy. Detailed notes were also taken about each interview. A post-interview reflective journal was written to help put the interview into context. The reflective journal was used to remind me of the context of what was shared during the interview. Each transcript was labelled with the date, time and, location of the interview. The transcripts were then reformatted for ease of use on NVivo Pro 12.

### **Deductive Qualitative Analysis**

Interview data were analyzed using a mixed deductive/inductive approach to thematic analysis (Braun and Clarke, 2006). A set of a priori codes based on the conceptual framework was applied to the data deductively. During the coding process, new codes were identified and incorporated with the existing codes.

The primary approach was based on the deductive nature of the analysis using a theory/concept-driven approach (Braun and Clarke, 2006). An initial codebook of a priori code was created based on the concepts and constructs from the critical disability theory, specifically Foucault's biopower (1973) and Andersen's Model of Health Behaviour (2008, See Figure 2). Utilizing NVivo Pro 12, transcribed data were transferred and arranged in NVivo nodes and codes. Through NVivo software, the transcripts were contextualized and categorized as repeated words, phrases, and concepts are coded and called nodes (collection of data with common areas of interest).

The nodes were derived from the created deductive codebook. After the initial coding process, the second round of coding was done to generate themes from the codes. The themes identified were used to construct a thematic analysis of the findings. Each interview transcript was re-read and coded according to the a priori codes identified. However, this study also puts more premium on the participants' understanding and perception of their experiences related to the a priori codes (Merriam, 2009). As part of the analysis, any new themes that were not present in the initial coding were incorporated in the final analysis. Data saturation was reached when no new codes were added using the query function on NVivo Pro 12.

### **Establishing Research Rigor and Trustworthiness**

This thesis has established research rigour in three ways: (1) research practice, (2) analytical rigour, and (3) procedural rigour.

To practice research rigorously, the researcher will engage in both descriptive and analytic reflexivity. Descriptive reflexivity includes meditating on the research setting, power relations in the field and the researcher-participants' interactions. On the other hand, analytic reflexivity refers to critically assessing the data in all studies (Brewer, 2000). Criteria for rigour in qualitative research are closely based on the investigation's paradigmatic underpinnings (Patton, 2016; Morrow, 2002). Based on the critical qualitative paradigm, analytical and

procedural rigour was evaluated using the trustworthiness and authenticity criteria suggested by Guba and Lincoln (1994).

Table 4

*Trustworthiness Criteria*

|                                     |   |
|-------------------------------------|---|
| Credibility (internal validity)     | To achieve confidence in the truth of findings (Guba & Lincoln, 1994), credibility was established by prolonged engagement with the participants, researcher reflexivity, cross-checking of interview transcripts, and participants' checks and the overall development of the thesis. Member checking was addressed by confirming some aspects of the interview as a representative of participants' perceptions. Participants were sent a copy of their transcripts, but only five participants responded. One of the participants commented on the length of the transcript. Another participant corrected the error on the timeline of the injury. Another participant with no email access was consulted over the telephone to the accuracy of the data in the transcript. |
| Transferability (external validity) | Guba & Lincoln (1994) suggest that "thick description" will provide a strong foundation to make a judgment about transferability. This was achieved by keeping field notes from the interviews, memos from NVivo of any information that affects the researcher (the researcher as an instrument), and providing the context of the researcher-participant relationship. Resources on their inquiries. Data from the memos provided the additional context of the participants' experiences.<br><br>A maximum variation in the sample was also used to increase the transferability of this study.  |
| Dependability (reliability)         | An audit trail was kept in this study, such as details of research activities and methodological decisions. This includes interview questions, interview notes that subsequently refined the use of prompts and probes, developing the initial codebooks, and re-coding the codes based on the memos in NVivo. The audit trail also included suggestions and discussions from meetings and correspondence with the thesis advisor. The reflective journal reflected on the interview (when and where it occurs) and the   |

|                              |   |
|------------------------------|---|
|                              | participant's reaction to the questions. This memo and journals informed some of the changes I have made in the data collection process, such as choosing a quiet space away from distractions and to avoid crowded public spaces, such as coffee shops.  |
| Confirmability (objectivity) | This refers to the degree of neutrality or the extent to which the study's findings are shaped by the participants (Guba & Lincoln, 1994). This was done by triangulating multiple data sources such as interview transcripts, memos, reflexive journal entries, and related literature. For instance, literature often noted the role of chronic fatigue in interviewing ABI survivors. Through literature and information gathered from ABI survivors, I have noted some ways to elicit relevant participants' answers. The results' analysis was grounded in the interview data using the participant's voice through direct quotations. |

Table 5

*Authenticity Criteria*

|                        |  |
|------------------------|--|
| Fairness               | This refers to the balanced view that presents all constructions and the values that undergird them. In this study, I have conducted member checking through emails and telephone calls on the data's accuracy. My professional role working alongside brain injured people and their families allowed me to have prolonged engagement with the brain injury community. However, I have acknowledged the importance of being reflexive about my role in collecting and analyzing the data. |
| Catalytic authenticity | This refers to a change of ideas. Findings from this study will be shared with the provincial government through the Department of Families Disability programs, social services, and regional health authorities. This will be done through presentations to various agencies and government units.   |

|                          |  |
|--------------------------|--|
| Tactical authenticity    | This refers to empowering the participants to take action. Participants will be allowed to meet with policymakers, stakeholders, and program administrators to encourage the findings' implementation. Participants will be sent a summary of this thesis upon completion. Interested participants will be given a chance to speak as part of the presentations that report to stakeholders and government units.  |
| Ontological authenticity | This refers to whether or not the participants' constructions are improved, matured, expanded, and elaborated (Guba & Lincoln (1994). Reflective journals that were kept show that participants just want responsive access to services. A review of the journal suggests that participants recognized that access to services for brain injury is a complex but solvable issue. This study hopes that participants will be more equipped in self-advocacy. In the process, they will reconstruct the dominant discourses on living with an ABI. |
| Educative authenticity   | This refers to determining if the research led to increased awareness of the range of constructions/perspectives. An oral debriefing was conducted after the interview. Debriefing notes show an increased understanding of the macrolevel issues that affect access to care. For instance, one participant stated that she was merely a passive recipient of services and planned to address the issue by being more assertive in accessing services.   |

### **Ethical Conduct of Research**

This study received approval from the University of Manitoba Research Ethical Board on November 22, 2019.

#### **Confidentiality**

Audio recordings, transcribed interviews, and field notes were reformatted into electronic files. To keep participants' privacy, pseudonyms were used in all data.

Data collected from the participants were kept private. Each participant was assigned an identification code number when consent to participate was obtained. The researcher used the identification code number on all data collection forms. In addition, pseudonyms were used in transcripts and quotations to ensure privacy and confidentiality.

Data were stored on a computer that is password protected. Only the research investigator and thesis advisor have access to the data. Audio recordings were erased once they were transcribed and reviewed. Transcripts and analysis were stored in the same password-protected computer. Copies of informed consent, identification code numbers, memos and journals were kept in a secured, locked file cabinet with only the researcher having access.

### **Informed consent**

A consent form was obtained from the participants who met the eligibility criteria. Participants were asked to explain their understanding of the study as a quick way to assess their functional capacity (See Appendix A). The researcher discussed the study's purpose, strategies for ensuring confidentiality and privacy, and risks and benefits. A copy of the consent form was given to the participants, and the researcher kept another copy. Participants were informed that they could withdraw their participation at any time.

### **Benefits and Risks**

Appropriate measures were taken to ensure that the magnitude of harm and discomfort in the research would not be more significant in and of themselves than those ordinarily encountered in the participant's daily life. However, given the nature of the data collection, possible risks included discomfort in responding to interview questions that may trigger stressful memories related to access to health and social services. While the majority of the participants reported a positive experience after the interview, five out of fifteen have displayed discomfort such as long pauses, fighting back the tears, short crying, and asking for more time to answer the question when asked about the “mechanism of their injury” and “on how their family and community viewed brain injury”. A list of services and resources were given to the participant during debriefing. The participant was informed that he/she could withdraw from the study or refuse to answer questions that may be too painful/stressful. Despite some difficulty in uttering their answers, none of the fifteen (15) participants refused any questions. Participants received a gift card worth \$15.00 for the time allotted to the interview.

### **Summary**

While efforts were made to widen the reach and broaden the inclusion of brain injury survivors from diverse backgrounds, this study acknowledges the limitations of data collection from participants. Brain injury survivors who have severe cognitive impairment and speech difficulties were not represented in this study.



### Chapter Four – Findings and Analysis

In this chapter, I will present the findings of the interview data. The interview questions were based on the conceptual and theoretical framework informing this study. This study involved a priori categories for the data analysis derived from the concepts from the conceptual framework. Unexpected themes that emerge from the data were also included in the analysis.

Table 6

#### *Participant Characteristics*

|   | <b>Total<br/>(n=15)</b> | <b>Winnipeg<br/>(n=8)</b> | <b>Rural (n=2)</b> | <b>North<br/>(n=2)</b> | <b>Homeless (n=3)</b> |
|---|-------------------------|---------------------------|--------------------|------------------------|-----------------------|
| <b>Recruitment Method</b>                   |                         |                           |                    |                        |                       |
| Doctor<br>(psychiatrist/specialist)         | <b>2(13.3%)</b>         | 2 (25%)                   | 0                  | 0                      | 0                     |
| Medical clinic, not doctor                  | <b>1 (6.7%)</b>         | 0                         | 0                  | 1 (50%)                | 0                     |
| Social service provider                     | <b>3 (20%)</b>          | 1 (12.5%)                 | 1 (50%)            | 1 (50%)                | 0                     |
| Shelters                                    | <b>3 (20%)</b>          | 0                         | 0                  | 0                      | 3 (100%)              |
| Community<br>posters/Online/email           | <b>6 (40%)</b>          | 5 (62.5%)                 | 1 (50%)            | 0                      | 0                     |
| <b>Highest Educational Level</b>            |                         |                           |                    |                        |                       |
| Grade 10                                    | <b>3(13.3%)</b>         | 1 (12.5%)                 | 0                  | 0                      | 1 (33.3%)             |
| High School graduate                        | <b>4(33.3%)</b>         | 2 (25%)                   | 0                  | 1 (50%)                | 2 (66.7%)             |
| Diploma/Trade/Certificate                   | <b>4 (26.7%)</b>        | 2 (25%)                   | 1 (50%)            | 1 (50%)                | 0                     |
| Bachelor's degree                           | <b>4(26.7%)</b>         | 3 (37.5%)                 | 1 (50%)            | 0                      | 0                     |
| <b>Ethnicity</b>                            |                         |                           |                    |                        |                       |
| White                                       | <b>8(53%)</b>           | 5(62.5%)                  | 0                  | 1<br>(12.5%)           | 2 (25%)               |
| Indigenous peoples<br>(First Nation, Metis) | <b>5(33.3%)</b>         | 1(12.5%)                  | 2 (25%)            | 1(12.5%)               | 1(12.5%)              |

|  |                   |           |          |          |           |
|--|-------------------|-----------|----------|----------|-----------|
| South Asian  | <b>1 (6.7%)</b>   | 1(12.5%)  | 0        | 0        | 0         |
| Filipino   | <b>1(6.7%)</b>    | 1(12.5%)  | 0        | 0        | 0         |
| <b>Employment Status</b>   |                   |           |          |          |           |
| Employed   | <b>3 (20%)</b>    | 3 (20%)   | 0        | 0        | 0         |
| Retired  | <b>2 (13%)</b>    | 0         | 1(50%)   | 1 (50%)  | 0         |
| Unemployed, on<br>Employment Assistance  | <b>3 (20%)</b>    | 1(12.5%)  | 0        | 0        | 2 (66.7%) |
| Unemployed, on<br>Employment and Income<br>Assistance (EI-A) for<br>People with Disabilities | <b>4(26.7%)</b>   | 1(12.5%)  | 1 (50%)  | 1 (50%)  | 1 (33.3%) |
| Unemployed, on Canada<br>Pension Plan-Disability<br>(CPP-D)                                  | <b>1(6.7%)</b>    | 1 (12.5%) | 0        | 0        | 0         |
| Unemployed, no income<br>support   | <b>2(13.3%)</b>   | 2 ( 25%)0 | 0        | 0        | 0         |
| <b>Income ( household)</b>   |                   |           |          |          |           |
| Under \$25,000   | <b>9 (60%)</b>    | 3 (37.5%) | 2 (100%) | 1(50%)   | 3 (100%)  |
| Over \$25,000 but below<br>\$65,000  | <b>5 (33.3%)</b>  | 4 (50%)   | 0        | 1 (50%)  | 0         |
| Over \$65,000  | <b>1 (6.7%)</b>   | 1(12.5%)  | 0        | 0        | 0         |
| <b>Private Insurance</b>   |                   |           |          |          |           |
| Yes  | <b>4 (26.7%)</b>  | 4 (50%)   | 0        | 0        | 0         |
| No   | <b>11 (73.3%)</b> | 4 (50%)   | 2 (100%) | 2 (100%) | 3 (100%)  |
| <b>Years since injury</b>  |                   |           |          |          |           |
| 2-5 years  | <b>8(53.3%)</b>   | 3 (37.5%) | 2 (100%) | 2 (100%) | 1 (33.3%) |
| 6-10 years   | <b>4(26.7%)</b>   | 4 (50%)   | 0        | 0        | 0         |

|                                   |                 |            |         |         |           |
|-----------------------------------|-----------------|------------|---------|---------|-----------|
| Over 10 years                     | <b>3 (20%)</b>  | 1 (12.5%)  | 0       | 0       | 2 (66.7%) |
| <b>Gender</b>                     |                 |            |         |         |           |
| Female                            | <b>6 (40%)</b>  | 5 (62.5%)  | 1 (50%) | 1 (50%) | 0         |
| Male                              | <b>9 (60%)</b>  | 4(37.5%)   | 1 (50%) | 1 (50%) | 3 (100%)  |
| <b>Age</b>                        |                 |            |         |         |           |
| 18-30                             | <b>3 (25%)</b>  | 2 ( 25%)   | 0       | 0       | 1(33.3%)  |
| 31-50                             | <b>6(33.3%)</b> | 3 (37.5%)  | 2(100%) | 0       | 1(33.3%)  |
| 51-65                             | <b>4(26.7%)</b> | 3 ( 37.5%) | 0       | 0       | 1(33.3%)  |
| Over 65                           | <b>2(13.3%)</b> | 0          | 1 (50%) | 1 (50%) | 0         |
| <b>Cause of Injury</b>            |                 |            |         |         |           |
| <i>Traumatic Brain Injury</i>     |                 |            |         |         |           |
| Motor vehicle collision           | <b>3(20%)</b>   | 3(37.5%)   | 0       | 0       | 1(33.3%)  |
| Falls                             | <b>1 (6.7%)</b> | 1 (12.5%)  | 0       | 0       | 0         |
| Sports/work-related injuries      | <b>1(6.7%)</b>  | 1 (12.5%)  | 0       | 0       | 0         |
| Assaults                          | <b>2(13.3%)</b> | 0          | 0       | 0       | 2(66.7%)  |
| <i>Non-traumatic brain injury</i> |                 |            |         |         |           |
| Stroke                            | <b>3(20%)</b>   | 0          | 1 (50%) | 2(100%) | 0         |
| Aneurysm                          | <b>4(26.7%)</b> | 4 (50%)    | 0       | 0       | 0         |
| Brain tumour                      | <b>1 (6.7%)</b> | 0          | 1 (50%) | 0       | 0         |

A total of seventeen (17) participants qualified for an interview for the study, with two (2) interviewees excluded from the analysis due to unreliable information. All participants were screened to determine their eligibility and decision-making capacity. The majority of the screening was done through telephone interviews, and two were done in person before the

primary interview was conducted. For the first excluded participant, the interview was going well until some parts were hard to follow. The other participant expressed himself initially, but his aphasia made it hard for him to follow throughout the interview.

The majority of the participants were White and living in Winnipeg. There is a significant educational variation with equal distribution of participants having completed high school, diploma/trade certificates, and university degrees in terms of education. Interestingly, 20% of the sample was from the homeless population. This was due to the research poster made available in almost all social service agencies in Winnipeg, especially in soup kitchens and homeless shelters. Concerning employment, 60% of the participants were unemployed, with two-thirds of those without a job having some income support. All of the unemployed participants without income support were still pursuing appeals with Workers' Compensation or insurance. The fact that only 20% of the participants were employed, despite the unemployed lacking any apparent physical disability, suggests they were more severely injured than they appear to be.

More than half of the participants (54%) had lived with their brain injury for 2-5 years. In terms of demographic characteristics, most of the participants were in the working-age group, although there was a significant variation in age groups. Over half of the participants were males between the ages of eighteen and sixty-five. The participants' cause of injury represented both traumatic and non-traumatic events. The majority of traumatic brain injuries were due to motor vehicle collisions. In contrast, brain aneurysm was the most frequent non-traumatic cause.

Table 7

*Themes from the deductive thematic analysis*

| CONCEPT OR<br>CONSTRUCT FROM<br>THE CONCEPTUAL<br>FRAMEWORK | THEMES   |
|---|--|
| Contextual factors  | Transportation, policies, health and social services systems |
| Individual factor:<br>predisposing                          | Demographics, social structure, and health beliefs           |
| Individual factor: enabling                                 | Geographical location and income                             |

|                         |   |
|-------------------------|---|
| Individual factor: need | The severity of the injury, health and social care utilization  |
| Power/knowledge         | Service user-service provider power relationship, knowledge translation/production about brain injury-related information |
| Language                | Use of the medical model in defining disability, medicalization, return to normalcy                                       |
| Access to care          | Proper diagnosis, acknowledging and responding to the ABI-related symptoms  |

The collected data and results for this study are presented and analyzed using the conceptual framework presented in Chapter 2. This framework is a combined model using Andersen's Behavioural Model of Health Care use (2008) and critical disability studies, which view access to care due to the dynamic interaction of contextual and individual characteristics mitigated by power/knowledge and language. The interview data were analyzed by examining the extent to which power/knowledge and language produce conditions that further disadvantage the contextual and individual factors of brain injury survivors.

The following section includes the presentation of findings and analysis using concepts from the conceptual framework presented in Chapter 2 (see Figure 3). Using the critical disability lens, specifically the Foucauldian perspective, the role of power/knowledge and language will be examined to access care.

### **Quantitative Analysis of Participants' experiences in accessing care**

The completed surveys were analyzed using frequency distributions of all the survey items. Results from the descriptive analysis show significant variation in participants' experiences in accessing care. To better understand the data, I cross-tabulated Table 8 with the demographic variables presented in table 7. While the findings are descriptive and not inferential, data from the survey generated salient results.

Table 8

*Participants' experiences of accessing care (quantitative survey)*

|  | <b>N=15</b> | <b>Never</b> | <b>Seldom</b> | <b>Some of<br/>the time</b> | <b>Most of the<br/>time</b> |
|--|-------------|--------------|---------------|-----------------------------|-----------------------------|
| Being refused treatment or services from providers   | n=15        | 6(40%)       | 7(46.7%)      | 0                           | 2(13.3%)                    |
| Health care facility/specialist needed is not available<br>in your area                            | N=15        | 6(40%)       | 0             | 0                           | 9(60%)                      |
| During appointments, you are allowed to ask<br>questions to your service providers.                | N=15        | 0            | 1 (6.7%)      | 8(53.3%)                    | 6(40%)                      |
| Service providers (doctors, therapists, etc.) explain<br>and help you understand your brain injury | N=15        | 4(26.7%)     | 1 (6.7%)      | 2 (13.3%)                   | 8(53.3%)                    |
| You have difficulty arranging transportation   | N=15        | 4(26.7%)     | 1(6.7%)       | 2(13.3%)                    | 8 (53.3%)                   |
| You do not qualify for the services you want to<br>receive.  | N=13        | 2(15.4%)     | 0             | 1(7.7%)                     | 10(76.9%)                   |
| You have difficulty remembering and locating the<br>services needed.                               | N=15        | 0            | 2(13.3%)      | 6(40%)                      | 7 (46.7%)                   |
| You are still waiting for the services that you need.  | N=15        | 0            | 2(13.3%)      | 6 (40%)                     | 7 (46.7%)                   |
| You are stressed and frustrated in finding services.   | N=14        | 0            | 3(21.4%)      | 2(14.3%)                    | 9(64.3%)                    |
| You do not know where to find help.  | N=15        | 1(6.7%)      | 4(26.7%)      | 6 (40%)                     | 4 (26.7%)                   |
| You have financial issues that make it hard to access<br>services.                                 | N=15        | 1(6.7%)      | 3(20%)        | 2(13.3%)                    | 9(64.3%)                    |

As shown in Table 9 above, participants were asked to rate their experiences with access to care from not having experienced the item (*never, seldom*) to have experienced it with varying levels of frequency (*some of the time, and most of the time*). The survey items were based on the constructs from the conceptual framework model presented in Figure 3.

*Being refused treatment or services from providers*

The survey findings revealed that the participants' least likely experience was being refused service (40%, never and 46.7%, seldom). Participants from outside Winnipeg, such as from rural and northern Manitoba, were least likely to experience being refused treatment or services from providers (100%, never). In terms of ethnicity, those who identify as Filipino and

South Asians were least likely to experience refusal of treatment and services from service providers (100%, never).

*Health care facility/specialist need is not available in your area*

In terms of the use of health care facilities and specialists, more than half (57%) of the participants reported not having any access most of the time. However, on the other hand, nearly half reported having no issues with health care facilities and specialist access. Based on the cross-tabulation results, those with an undergraduate degree are much less likely to experience healthcare facility or specialist unavailability (75%, never) than those with Grade 10 or less (67.3%, most of the time). In terms of location, ABI survivors from Winnipeg are much less likely to experience service unavailability (75%, never). This could be because most specialized services are located in Winnipeg (Shared Health, 2019).

On the other hand, Indigenous survivors are more likely to experience the unavailability of specialists or facilities (80%, most of the time). While those receiving CPP were least likely to experience unavailability (100%, never). ABI survivors who are now retired were most likely to experience unavailability (100%, most of the time). Considering age as a variable, the 18 to 30 age group were least likely to experience unavailability (66.7%, most of the time). Those without insurance were most likely to experience unavailability of facility/specialist (63.6%, most of the time).

*During appointments, you are allowed to ask questions to your service providers.*

The majority of the participants reported being allowed to ask questions from their service providers. Data from the interview revealed that most participants' questions to their service provider were about the unknowns about brain injury and their recovery trajectory. The homeless population and young survivors (18 to 30 group) are most likely to be allowed to ask questions (100%, most of the time).

*Service providers (doctors, therapists, etc.) explain and help you understand your brain injury*

There were varied responses concerning service providers explaining and supporting the participants to understand their brain injury. Based on cross tabulating the data, the homeless population group of ABI survivors were the group most likely to receive explanations and help to understand their brain injury (100%, most of the time). This result is consistent with this group being most likely to be allowed to ask questions, as shown in the previous item (100%, most of

the time). On the other hand, participants who are retired and over 65 years of age are least likely to receive help from their service providers in understanding their brain injury (100%, most of the time).

*You have difficulty arranging transportation*

Concerning transportation, more than half of the participants have difficulty arranging transportation (53.3%, most of the time). Participants from northern Manitoba were most likely to have difficulty arranging transportation (100%, most of the time). Shared Health (2019) reported the ramifications for access among rural and northern Manitoba participants. A significant number of patients from outside Winnipeg travelled for care and to access specialized services (Shared Health, 2019). For ABI survivors, they have to arrange the travel to access specialists and major procedures often located in Winnipeg. Without family and formal supports, distance delays access to care as travel is expensive and time-consuming (Pachkowski et al., 2009). It is also worth noting that participants who were retired and not currently working were most likely to find themselves without transportation (100%, most of the time). Similarly, those with grade 10 or less education (100%, most of the time) and those without private health insurance (100%, most of the time) were most likely to have difficulty arranging transportation.

*You do not qualify for the services you want to receive.*

It is worth noting that a large majority of the participants have issues with qualification processes in accessing services (76.9%, most of the time). This result could be attributed to participants being highly functional and showed less or no physical disability sign. A cross-tabulation analysis showed that participants from outside Winnipeg, such as from rural and northern Manitoba, were most likely to not qualify for services they want to receive (100%, most of the time). Similarly, participants who belong to the 31 to 50 age group and the over 65 age group were most likely to not qualify for services (100%, most of the time). Not qualifying for services was also higher among participants receiving EI-A and those without private health insurance (100%, most of the time).

*You have difficulty remembering and locating services needed*

There was significant variation in participants' responses, denoting difficulty remembering and locating services needed. Despite cognitive and executive impairments often reported as difficulties among ABI survivors, the sample reported various injury severity levels. However, these difficulties were more apparent among participants who are not working and



young survivors aged 18 to 30 (100%, most of the time). On the other hand, those receiving CPP-Disability were least likely to experience difficulty remembering and locating services needed (100%, most of the time).

*You are still waiting for the services that you need.*

Responses were varied on participants' experiences waiting for the services they needed. However, those living outside Winnipeg, such as in rural and northern Manitoba, were most likely to experience waiting for the services they need (100%, most of the time). Participants receiving EI-A and those without private health insurance were also most likely to experience waiting for the services (80%, most of the time). Similarly, male participants were most likely to experience waiting for services (75%, most of the time).

*You are stressed and frustrated in finding services.*

The majority of participants reported being stressed and frustrated in finding services (64.3%, most of the time). In particular, male participants were most likely to experience stress and frustration over services (75%, most of the time). In comparison, those receiving CPP-D were least likely to experience stress and frustration in finding services (100%, never). Young survivors ages 18 to 30 (100%, most of the time) and those with undergraduate degrees (100%, most of the time) were most likely to experience stress and frustration in finding services.

*You do not know where to find help.*

Although there was a significant variation in the participants' knowledge of finding help, those living outside of Winnipeg, particularly in the rural area, were most likely to experience not knowing where to find help (100%, most of the time). Participants who are retired and over the age of 65 were most likely not to know where to find help (100%, most of the time).

*You have financial issues that make it hard to access services.*

The majority of the participants reported finances as barriers to access to care (64.3%, most of the time). Participants reported that out-of-pocket expenses deter them from accessing necessary services that are not available through provincial health coverage. Participants who belong to the homeless population (100%, most of the time) and those receiving both EI-A and EIA- for people with disabilities (100%, most of the time) were most likely to experience financial issues that made it hard to access services. On the contrary, those receiving CPP-Disability (100%, never) and those who were retired (100%, never) were least likely to experience financial issues in accessing care. Male participants were most likely to experience

difficulties financially (87.5%, most of the time). Also, those without private health insurance (87%, most of the time) and those with income under \$25,000 (81%, most of the time) were most likely to experience financial issues in accessing care.

### **Qualitative Analysis of Participants' experiences in accessing care**

#### **Theme One: Contextual characteristics**

In this study, contextual factors include organizational factors, transportation, travel time, the waiting time for health care, resources available within the community, and health policies. Within this theme, subthemes include (1) working through the maze and (2) uncoordinated system of care, (3) transportation issues, (4) geographic location, (5) funding system and (6) morass of eligibility requirements.

##### *Working through a maze*

Seeking access to care can be exhausting, especially when services are not readily available. More so when cognitive and behavioural capacities have been compromised so that navigating the often-fragmented system is like working through a maze, blindfolded. For many Manitobans with brain injury, gaining access requires the individual's effort and the presence of a support system, such as family caregivers, case managers, and community workers.

The participants have reported that managing brain injury's impact on their lives is one of the most challenging aspects of seeking health and social services. The majority of the participants use the term “new normal” to describe the accommodation and coping needed to the changes they encounter due to their disability.

As evident from the interviews, access to care become problematic when the individual's behaviour and capacity to communicate, organize and remember are affected. On the other hand, participants reported that these deficits are also unknown to health and social services providers, impacting participants' access to care. This lack of knowledge on the changes associated with behaviour and cognition affected participants' ability to access services and appropriate responses to their needs. The most common cognitive and behavioural impacts described by participants included memory impairments and impaired executive functions. These cognitive deficits frequently result in “decreased ability to attend to several pieces of information or manage several activities at the same time, to learn new information or skills, to remember planned activities, to concentrate over a long period of time, to remember what somebody just

said” (Toglia & Golisz, 2017, p. 23). The extent of the ABI impact has implications in terms of frustration tolerance in seeking access to services. McAllister (2008) suggests that individuals with cognitive impairments, such as brain injury survivors, have developed a heightened sensitivity to the environment in which they live. He refers to this as “stimulus boundedness, as a tendency to be very sensitive to events in the immediate environment, perhaps related to difficulty with components of attention, including complex, selective, and sustained attention, and resultant problems in prioritizing incoming stimuli and in gating out stimuli that would ordinarily be deemed of secondary importance” (p.7). What may typically be more comfortable for a non-brain injured patient to undertake, such as filling a form, cancelling and remembering appointments, is taxing to do for someone battling with myriad issues that hinder her or him from attending to care.

Too extreme emotions like rage. Also, loss of memory. I will be talking with the government knows different government departments and stuff. And they will ask me my phone number, and I will be able to tell them what it is, and then they will get angry at me or how come you cannot know your phone number. And so, every day just feels like an incredibly different struggle than it was before the injury. And then, on top of that, again, what other people have described to me, not what I have put out, is sometimes considered an invisible wound. And that is difficult for, say, Manitoba health services or different agencies to receive some support to gain a base and not be in homeless shelters and soup kitchens, which are a struggle of their own.

The impact that brain injury has on the participants’ cognitive and behavioural performance makes it even more challenging in accessing care. One participant, who described herself as reasonably intelligent, finished two degrees before and after her injury, often finds herself in the same dilemma as Adam in terms of communicating her needs:

And I found out that sometimes, it is difficult for me to remember and hard to communicate what I wanted and feel that I was heard.

There is a tendency to overlook cognitive and behavioural changes because these symptoms are frequently not visible. Dawn explained that she was “out of it” even when doctors sent her home. She recounted her experience as follows:

So, what happened was a lot of time at the hospital. When I came out of it, I would wake up, but I had been awake. So, I was talking. That was frightening that I was busy talking away. And then I see someone like you, and then we would have a little talk. And then I would fall asleep again, but I do not think I was sleeping, but I keep talking, but I was not aware. And then I would come back again, and it would be like a different person, but it

was a different day, and I know. When people said the doctor was here yesterday and asked you how you were, you said you are fine. I even signed papers for a lawyer that I do not remember at all. But I was deemed by the medical professional that I was okay to sign, but I was not.

Often, as ABI survivors transition back to their community, their support system, such as family members, plays an essential role in the survivor's access to care. Family members take on different roles to support their loved ones by providing physical, emotional, social, financial, and domestic support. However, survivors who live on their own find that they need a formal support system. One participant from Northern Manitoba shared her struggles. She stated:

I have trouble when I am tired or when I am being introduced to something new or having to do something that requires much thinking much brainwork. And they get exhausted. Sometimes my nurse practitioner fights for me and gives me a ride either to home care or I will not. My daughter is when she can. And they also have their own lives, right? Yeah, they can't be just waiting on you for everything.

Similarly, Dawn, who lives in Winnipeg, shared the same issue on the lack of a support system.

The union at that time [while on short-term disability] would call me and tell me what to do. That is what I needed. Most people, I did not need help cooking. But what I needed was somebody to say did you pay your Visa bill? When was the last time you replace your furnace filter? Like just things like life navigation.

#### *Uncoordinated system of care*

The findings show that the context of the health and social care system and organizational structures contributed to accessing services. After one has incurred a brain injury, the wide range of consequences requires a complex multidisciplinary team of services post-injury. Ideally, brain injury recovery follows a seamless continuum of services from acute care to community-based services (Owens, Lynch, O'Leary, Lowery & Kerin, 2018). ABI presents a unique and distinct challenge in service provision. ABI survivors are faced not only with the treatment of symptoms but are also confronted with physical, social, financial, and psychological barriers (Owens et al., 2018). Although these barriers can be addressed through community support services, participants shared that these community-based services are often limited, or in the case of rural areas, non-existent. Cor, who incurred a brain injury 18 years ago, did not receive support after being discharged from the inpatient rehabilitation centre. She shared:

I wanted, they should have, like way back when I got out. They should have some kind of counselling or support or something because you are out of it. I thought I was okay, because well, I was a single mom. I had been in hospital and rehab at Seven oaks. I had to get home. Then they took my licence away from me, and I was a sales rep. I need a licence. And I went further in debt, with no support, nothing. Nothing. And uhm, I thought I was OK, but I was not, you know.

Despite the time passed, this lack of information on finding and accessing resources was identified as a barrier by another participant who had a brain injury two years ago. Bailey shared his family's experience as follows:

So, my GP has acknowledged, I think, to a certain point, yeah, that there is something wrong, but not immediately. No, no one's ever referred me to anywhere. Specifically, for that, yeah. Anything that we've done, we have researched on our own.

Based on the interviews, access to community-based services and specialists such as neurologists and neuropsychologists depends on the general practitioner's influence (GP). For instance, Dawn had to change GPs to get a referral to a neurologist. She shared her experience as:

I have another doctor before this one, but I got the same answer. OK, is there somebody? There was a neurosurgeon even back then, but if the GP does not refer you, you can't.

Because GPs are the first point of contact in the healthcare system, they ultimately affect participants' recovery trajectory. For instance, the homeless population who have difficulty accessing their family doctor has to use walk-in clinics to ask for service referrals. Adam, who lived in the suburbs before becoming homeless, has no resources to visit his former GP.

I have been going to the walk-in clinic because I have no resources to get to my family doctor. Like, you know, it would be helpful if this patient (Adam) had a telephone so he could be in contact and receive his appointments. It would be helpful if he had a bus pass to get to places to get to the doctor because the doctor is out by the perimeter on the south end of the city. And I'm over here and like I described to you for one of my surgeries. I had to hitchhike Get to my surgery because there are no funds.

Allan, another homeless participant, lost his doctor and has been going to the Emergency Department at Health the Sciences Centre (HSC) to access care. According to Allan, "when you live on Main Street, you do not get services". Allan reported that it is difficult to find a permanent doctor because he has no permanent address.

For the majority of the participants, access to care post-injury has been frustrating and overwhelming. Based on the interview data, access to care is affected by the participant's ability and the lack of services available following discharge from hospitals and/or in-patient rehabilitation facilities. Dawn, who lives alone, had a significant brain hemorrhage and almost died on the operating table, was released from the hospital straight to her home. She shared that she did not receive the health and social services needed when she was discharged from the hospital.

Yes, the whole time after. Probably, 2.5 years after I had my brain injury, because I didn't feel like the medical community supported me. Oh well, and social services. It would have been very nice to have a social worker attached to me before leaving the hospital and following up.

Concern about lack of follow up was the same sentiment expressed by Natalie after her brain surgery at Health Sciences Centre (HSC). She was sent home to Southern Ontario but declined the transfer to a local hospital in her hometown in Ontario. Without a GP, there was no follow up from either Winnipeg or Ontario. Despite her surgery, she never had any specialized services such as therapy, as she shared:

And there was basically no follow up at all. My GP was on his way to retirement and never really dealt with someone like me before. Because I was walking fine, my language is all there, and I just have short term memory loss. But I didn't go through any occupational therapy for memory loss, vision, cognitive processing.

For Adam, who also struggles with Post Traumatic Stress Disorder (PTSD) from the assault that gave him brain injury, not having any follow up after a major hospital operation felt like the medical system had given up on him. He shared:

It feels like what often people say where the ball is dropped, or there is no follow-through, or they are expecting me to be someone who can constantly call and nag constantly and prod and push to get things done.

Conversely, participants like Kaye and Cor were admitted to an inpatient rehabilitation center following the hospital's treatment. Both had access to well-coordinated specialized services, such as speech and language therapy, physiotherapy, occupational therapy, neuropsychology, counselling, physiatry, music therapy. Until Kaye and Cor were sent home, they realized that community-based services and specialists, other than home care services, were

not readily available. After having spent weeks in in-patient rehabilitation, Cor realized that inpatient care was all there is in terms of services.

Like, even the neurosurgeon. Even back then, I just want the neurosurgeon to come and talk to me after and book an appointment after the hospital to explain things. But yeah, I went through another testing at the Health Sciences Centre. I went through what it is like for my eyes; they did other tests and that. But nobody ever really followed up as far as the brain, in explaining

While Kaye described a positive experience at the rehabilitation centre, sharing that “the services that I have learned a lot was when I was at Riverview. My care there was really good, the people there were really good”. Her experience with community-based services, specifically home care, was less favourable.

We had multiple homecare, some were nice, but I had lousier home care. One time, I had someone who wants to watch tv all the time. She wants to watch Bold and Beautiful. But she got so comfortable, and she would take the blanket and cover herself and sit there and sleep with me around. It was terrible. I never want homecare anymore

According to Karen Thomas, an ABI-trained social worker, “70% of our discharges go home- most with home care, but the issue is they are not trained to manage brain injury nor have the resources. Homecare is a community-based service that does its best and carries the brunt of the load for moderate to severe injuries” (A. Thomas, personal communication, May 21, 2020).

Participants who had been hospitalized and accessed in-patient rehabilitation remarked on the positive experience and efficiency of the services they received. However, they stated that treatment was focused on their physical deficits and not the overall aspect of their recovery. A study conducted in Ontario, which reviewed the community and health services for people living with ABI, revealed that ABI survivors were at an increased risk of depression, anxiety, and other psychopathologies, which added to the cognitive, behavioural, and mental health services they needed. (Munce et al., 2014). For Dawn, the significant change in her life and having gone through brain surgeries impacted her mental health. However, she could not find nor qualify for any services related to mental health. She shared her frustration as follows:

Impossible, absolutely impossible. It was like, I mean if it was existing services I already had, like my osteopath, I had my therapist, but yah no, there was nothing. There was no referral to things like groups about anxiety or even a look at what therapies could impact anxiety. Or if I ever had anxiety.

The majority of the participants expressed a wish that there had been a one-stop-shop for all brain injury services to help them recover. The participants believed their quality of life would have been different. Trace, dealing with her post-concussion syndrome's persistent symptoms, shared her frustration over long waiting lists and bouncing from one service provider to the next.

For the most part, had we had a clinic specifically for brain injuries in Manitoba that had multiple disciplinary practitioners to assess and say, Okay, we suspect you have a brain injury. We are going to help you; we are going to go through this this this this [refers to different kind of therapies].

Unlike Trace, who is still struggling to obtain a neurologist's diagnosis, Dawn was admitted to the hospital and received a diagnosis. But despite that, she was still struggling to gain access to services related to her brain injury. A centralized service with a coordinator would have made navigating the healthcare system easier and seamless.

Like a map! A service map. I was then circling the ones applicable to me. Can I access mindfulness stress reduction, for example, or is that go to work? What could I have done? Do I need someone to talk to? Do you need a therapist that understands brain injury?

One of the participants had the benefit of a centralized service via CancerCare Manitoba. William, who had a brain injury from a brain tumour, received timely and well-coordinated services. Despite living in a rural area, a social worker was assigned to William, who worked with him through every step of his recovery. He was surprised to find that his experience was the exception and not the rule when he attended a brain injury support group in Brandon. William expressed how navigating his new life was more manageable with the caseworker:

My good experience is with my social worker; that is positive in my life. Yes, she does. When I needed help, she asked me to talk on the phone, connect me with my doctors, or arrange transportation or a break if I want to take a bus.

This scenario demonstrated the medical and health advantage of coordinated delivery services. Yet, there was more evidence of a convoluted process that participants must endure locating the required services. For instance, Bailey shared that doctors work in isolation from each other, and no communication between GPs and specialists occurs. With brain injury issues concerning memory, participants have to make sure they have a family member or close others



with them during appointments because the onus of facilitating communication with doctors is left to the patient.

I was referred to another neurologist, and I have only seen him twice, once for the initial consultation, and the second time was just to close *the* file, and he had sent a report to my physician. When I went to see him, I brought him a list of the things that I was experiencing because of my memory loss, I always forget. So, I brought him a copy of the report about the electrocution and brain injury. It looks like he has not even seen the files.

There was a general sense of bewilderment regarding the absence of a coordinator or entity that monitors survivors' movement from hospitals to in-patient rehabilitation to community services. Although Manitoba has a provincial strategy for stroke, a broader strategy for acquired brain injury that sets out a framework on service delivery, such as a system that coordinates all services, or advises where to go for services, and explain what services survivors need, does not exist (Manitoba Health, Seniors and Active Living ([MSHSL], n.d.)

Without knowing available services, participants felt a significant burden, fear and anxiety over not having any information. In Bubbles' case, living in Northern Manitoba makes it even more challenging as no specialist services are available in the north, let alone brain injury services.

I think that the north, in general, lacks absolutely everything. And there is not-- I do not know how to describe it. There is no support here. Yeah. For people with brain injuries, people with any kind of disabilities. And whatever support there is, is restricted. Yeah. Like, there are services for kids or for people who live on the reserve. But there is no crossing. It is like, well, this is my boundary. And you do not fit within my little box. So, I cannot help you. And I cannot tell you where to go with it.

This is consistent with the literature that identified the need for coordinated and accessible services, especially for those living in rural regions (Chen et al., 2017). In the current study, two participants were from Northern Manitoba.

Participants find it even more perplexing when the service providers who were supposed to be the experts do not know what services are out there. Considering her future's uncertainty, Bubbles expects service providers, especially medical professionals, to prepare ABI survivors for their recovery journeys. For instance, prior to her brain hemorrhage, Dawn was perfectly healthy but incurred a brain bleed that almost cost her life. She still experiences residual shock and speaks of her anxiety that her doctors do not have answers regarding her condition. Dawn stated,

“and I was like, is this gonna happen again? Am I gonna go home and this is going to happen tonight? And they were like “we don’t know”.

For some survivors, brain injury affects their ability to process and understand information, often resulting in taking a long time to read and understand written information (MBIA, 2018). However, this is not well known among practitioners. More often than not, participants were sent home with information packages that were neither helpful nor practical at that point in their recovery. As a result, participants felt confused and adrift as they struggled to return to their pre-injury life.

I think some stuff of that will be, like do not send me home with a giant thing of papers and pamphlets and stuff. I can't absorb this. Like I still have it. Ok. All these services, none of which I am qualified because I did not need physical rehab. But I say, maybe create a pathway like “are you experiencing this?”

This finding run parallels the results of the study conducted by LeFebvre et al. (2005). They found that inadequate knowledge of available resources and lack of a centralized source of information are two of the most cited barriers to access to care.

In addition to limited service provision, timing and responsiveness of services may have exacerbated the long-term consequences of survivors’ brain injury. Even with a neurologist, Orlando still had to wait for close to eight months for an appointment. He spoke of his experience as follows “I went to the Vic [Victoria General Hospital] because my arm was completely numb. I have booked to see my neurologist since the spring, that was April 2019, and my appointment was last January 2 [2020]”

The majority of participants had to take the initiative in finding the services that they needed. They highlighted the lack of information, especially from their general practitioners, on what services are available in their area.

Faced with urgency and the complexity of her persistent symptoms, Trace felt that six months waiting to see a neurologist would just exacerbate her condition. After calling several times a day, she got on a cancellation list. Trace said, “So you have to force yourself in. You have to be the gatekeeper of your own (health)”.

Despite the negative experiences, participants recognized that service providers are too inundated with heavy caseloads to attend to their needs adequately.

I can't find anybody who has time. I've tried to get the people here at Siloam<sup>3</sup> to come with me to Rorie<sup>2</sup>; they don't have time to go to the unemployment center. They say they are so overwhelmed. And then they just tell me to take a seat, and someone will come and see me. And I sit right there. And I talked to them, and I have it. You know, what, a scheduled time. And they had me sit there all morning, all day, eight hours just sitting there. And then I go and ask them, and they go, Oh, we thought you left. So we did not come and get you.

### *Transportation issues*

Access to care is also heavily influenced by the availability of transportation. Barriers to transportation often lead to rescheduled or missed appointments or missed or delayed medication. For instance, Bur waited nine (9) months to get an appointment with a neuropsychiatrist only to miss his appointment because of transportation problems. He shared:

I was supposed to go there. But with my brother, but my brother didn't come with me. Yeah. And there was no ride and no available, so I kind of didn't go. I never get a chance because I missed St Boniface [doctor] appointment. So, it's kind of out of the way. Yeah, because of my memory, specific bus routes were a problem for me. So, because of that case, I did get to see that person [the doctor].

These consequences lead to poorer health outcomes as missed appointments and procedures exacerbate unmet needs. In general, living independently goes hand in hand with having access to transportation. The majority of the participants in this study lost their capacity to drive. While others maintained that they still had their driver's license, they also had no financial means to afford a car to drive. According to Rapport (2008), change in driving status is typically abrupt, with little or no time to adjust or plan compensatory means of transportation to facilitate what they need and want to do after an injury. Having family support enables an easier transition. For example, although Bailey felt losing his driver's licence meant losing independence, he had his wife chauffeur him around since the injury. However, with the change in their financial situation, transportation was affected. He shared, "Well, it is going to get harder as my wife is looking at going back to work. Transportation is going to be a problem. There's the financial end of it, it's going to be an issue".

While participants such as Bailey who live in urban areas have access to public transportation services, brain injury's cognitive effects, such as dizziness, fatigue, and balance

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<sup>2</sup> Employment and Income Assistance Central Intake, 111 Rorie St., Winnipeg

<sup>3</sup> Siloam Mission

issues, make it more challenging to ride the bus. Trace, who lives at the far end of Winnipeg, had to take three buses to go to her medical appointment. She shared that “the stopping just on itself again because I’m still dealing with a fair amount of whiplash too and nausea and the peripheral issues-- I cannot do that”. Despite the need for services, she had to reschedule appointments to fit her husband’s schedule to take her to the doctor.

Although Handi-transit<sup>7</sup> is available to access, brain injury survivors often are not eligible for service. Fatigue, memory issues, cognitive impairment and behavioural problems are not considered under eligibility criteria (“Application for Handi-transit,” 2014). Individuals with cognitive disabilities alone are not eligible for Handi-Transit unless it is coupled with mobility issues such as inability to walk at least 175 metres at all times or if memory issues are related to Alzheimer’s and Related Dementia (“Application for Handi-transit,” 2014). While Brandon’s and rural areas’ Handi-transit were less specific on cognitive disability (“Handi-transit information,” 2020), the medical doctors’ functional assessment form had to be completed before accessing the service. Bubbles, who lives in Northern Manitoba, shared that Handi-transit application has been an issue for a long time. She explained:

City transit here has been an issue for a couple of years now and including the Handi transit. And I think the contract is out to a place called the Juniper center, whose priority is for their residents and clients.

Despite the inability to drive, brain injury survivors’ lack of physical manifestations of their disability excludes them from accessing services systematically created to benefit mostly those who have physical disabilities alone.

### *Geographic Location*

Manitoba’s population is highly rural, with 44% sparsely distributed across geographies with less than ten people per kilometre (Shared Health, 2020, slide 109). The distance travelled to access major procedures, and specialists’ services become problematic for survivors who live in the rural area. For instance, Bubbles has been consulting with her specialists in Winnipeg using telemedicine via Manitoba Telehealth<sup>3</sup>. But when her condition required her to see her neurologist in person, she had to plan her 10-hour trip to Winnipeg, which resulted in logistical

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<sup>7</sup> Handi-Transit is a service of Winnipeg’s public transit system that offers accessible transportation for individuals who meet one or more of the eligibility criteria (Winnipeg Transit, n.d.).

challenges related to transportation, accommodation and interruption with her caregiver's employment.

I was on a medical flight when I had my procedure. They also flew me back to Thompson to make sure I was stable. But medic flights are only available for the patient with emergency cases. For follow-ups and non-urgent appointments, I have to take an overnight bus to Winnipeg.

Brain injury survivors from rural areas may face a unique barrier due to disability and specialist services in urban areas. Rose, who lives in one of the reserve communities, had to move away from her family and community to receive care from an in-patient rehabilitation unit located two and a half hours away from her home. On the other hand, John Wayne, who spent close to a year at an in-patient rehabilitation centre, was discharged to his home in Northern Manitoba. Although he had homecare services and accessed Manitoba Telehealth, specialist services are still located in Winnipeg. Being elderly and living alone, his children decided to permanently relocate John Wayne to Winnipeg to be closer to services. As John Wayne said, "I did not want to sell my house. I lived there since I started working for X, but what can you do, eh?"

These findings are consistent with the report published by Shared Health, which says that patients receiving neuroscience services have experienced inconsistencies in care delivery and access where there is significant variation in the availability of rehabilitation services outside of Winnipeg, particularly for stroke and ABI (Shared Health, 2019, p. 167). Furthermore, the report also indicated that the majority of inpatient services (neurosciences) are delivered in Winnipeg Regional Health Authority (WRHA) with increased travel requirements for patients in rural and northern Manitoba (Shared Health, 2019, p. 167).

Shared Health (2019) recognizes the challenges in accessing care closer to home, with 58% of non-WRHA patients going to Winnipeg for inpatient care (p.167). However, the inconvenience of travel for care is worsened by a lack of financial resources. Bubbles described her experience crowdsourcing for money when her funds were not enough.

I had to come to Winnipeg in January for a test, and I have to go on an overnight bus from here. I was on the bus all night and got to Winnipeg, and a friend picked me up and took me for breakfast and drop me off at HSC. When I was at the reception, I almost collapsed, but they quickly got me help. After I finished my test, EI-A book me a room for a day at Canad Inns to rest before I take my night bus back, but Canad Inns said we do not have day rooms here. I can't wait till 3 pm, so I said, oh my god, what am I going

to do for 4 hours? The only thing I could do was sit in the hospital and sat there, picked up stuff to eat and then wasted my time on big couches. Then I went down to get a bite to eat, and then I went to sleep. When I got back this morning, and there is no money in my account. If I had no idea how much income assistance was put into my account, I think it was only \$15 per supper. So, I have no money for breakfast, nothing to eat, so I went on Facebook and posted that I am in Winnipeg and I have no money I need to eat, my sugar is crashing. And then, within an hour, a stranger came up to me and gave me money. My friend came into the city, took me out for lunch, and dropped me off at the bus station. Even on the bus, someone gave me an envelope and walked away. I have no clue who these people are but thank god they are. If I did not have people helping me, I would not have anything to eat

### *Funding system*

Manitoba is a province composed of approximately 1.38 million people (Government of Manitoba, 2020). Like the rest of Canada, we have the privilege of having our medically necessary basic health care funded by the public and universally available. In Manitoba, the health services are regulated by the Department of Manitoba Health, Healthy Living and Seniors (MHLS). Services are provided on a “prepaid basis, without direct charges at the point of service” (Health Canada, n.d., para. 28).

However, services deemed necessary for rehabilitation for brain injury survivors such as occupational therapy, physiotherapy, vision therapy, speech and language therapy are not covered outside of hospital and care facilities. According to Manitoba Physiotherapy Association (MPA), the *Physiotherapy Act* identifies physiotherapists as “primary care providers, as such anyone seeking physiotherapy can do so without doctor’s referral” (“Frequently Asked Questions,” n.d.). Manitoba Health covers physiotherapy services provided through hospitals and care facilities as outpatient rehabilitation for a select list of clinical conditions. Otherwise, access to physiotherapy services can be obtained through third party coverage or out of pocket payment (MPA, n.d.)

Data from the interviews revealed that the path to access to care for brain injury survivors differed in terms of the severity of the injury and the funding model reported by participants. Despite the contention that we have a universal health care system, data confirm Colantonio et al.’s (2010) hypothesis that Canada’s ABI healthcare system is two-tiered. Participants who were injured through motor vehicle collisions or workplace accidents may receive benefits and medical services through compensable funds. Out of 15 participants, ten are collecting disability benefits through Employment and Income Assistance and/or Canada Pension Plan- Disability.

The other five participants have access to private funding through their private insurance (3), Workers Compensation Board (1), and Manitoba Public Insurance. The extent of services that were accessed and received depended on the source of funding. Services such as extended physiotherapy, occupational therapy, case management, and psychotherapy were provided extensively and quickly when insurance and compensation were involved. Participants who received services through publicly funded programs such as Natalie and Orlando are still waiting for occupational therapy and neuropsychological assessments. These services are necessary for them to access other services that needed proof of their disability. At the time of the interview, both Natalie and Orlando were still waiting for a referral to occupational therapists from their GPs. Natalie had been waiting for almost a year to see a neuro-ophthalmologist.

It would be nice not having a long waiting list for neuro-ophthalmologists. The long waitlist and arranging it around your work schedule are tough!

In a report published by Shared Health (2019), overall wait time for rehabilitation has increased in the past three years, with neurosciences patients having the highest percentages (p.167).

Participants who were funded through insurance and compensation had, at one point, been assigned a case manager. The case manager's job is to coordinate various services for the individual to access, such as assessments, therapists, counselling, and return to work programs. With this funding model, there is faster access to services than public funding through Manitoba Health, requiring referral and being placed on a centralized waiting list for services.

For Trace, MPI authorized up to 25 treatments from physiotherapy and chiropractic providers as soon as she filed her claim.

I saw a physiotherapist, occupational therapist, and chiropractor right after my injury. The doctor writes I had a possible concussion but said I had the stage 2 whiplash. When I got to the Sport for Life concussion clinic (which I paid for), it was yes, and you have had a concussion. So, what I hear is concussion concussion concussion? The only one I didn't hear that from was from the MPI physiotherapist.

For instance, occupational therapy and physiotherapy are services that literature on rehabilitation management found to be important in brain injury recovery (ERABI, 2018; Colantonio et al. 2010, Chen et al., 2017). In Manitoba, publicly funded physiotherapy and occupational therapy can only be accessed within the hospital and care facilities (Manitoba

Physiotherapy Association, n.d., Government of Manitoba, n.d). Survivors who want to access these services need to wait for a referral from doctors that could take anywhere between three to six months, or they must pay out of pocket for this service.

At the initial onset of the injury, participants with private funding (compensation and insurance) reported receiving quick outpatient rehabilitation services following injury. Based on the participants' accounts, only those with WCB and MPI coverage could receive specialized services such as neuropsychological assessments, vision therapy, vestibular therapy, occupational therapy, psychotherapy/counselling, prescriptions, and case management services. In Manitoba, these services are typically offered in an in-patient facility or accessed through a fee-for-service basis. However, Bailey's and Trace's involvement with WCB and MPI was described as stressful. They felt that the services they received were used not to help them but to gauge their eligibility for the benefits. For instance, Trace shared that:

I also learned that some of the brain injury aspects that I am dealing with might not have been prevalent in the first week, two weeks, three weeks. If I believe what MPI says that there is no possible way, I could have a concussion because I never hit my head. Well, that is a bunch of BS, and we know that. So, the reality is when it comes to our healthcare in Canada, there is no teamwork. There is no teamwork

While neuropsychological assessment tests are beneficial towards recovery and not available through public funding, the tests are often used as an assessment to determine eligibility for benefits. Based on his experience, Bailey shared:

I am still experiencing the same symptoms and picking up new ones. But as soon as WCB received my neuropsychological report, my benefits were cut off. They pretty much all of them have ignored my input. I gave the information to Dr. X [neuropsychologist]. I am pretty sure. I do not know if she referenced it at all when she did a neuro report for me.

The ongoing appeal process for benefits and abrupt interruption of benefits and services created more frustrations, worsening Trace's and Bailey's ongoing persistent symptoms. For instance, the delay in access prolonged Trace's symptoms, affecting her eventual return to work.

There are some deficiencies with MPI. There are some nice individuals. They have to do, however, do your darn due diligence. Yeah. And I have reports from specialists to say, and these are the struggles that are true [persistent symptoms]. But MPI told me you don't have a brain injury. The reason I have headaches is that I have whiplash. So, they cut off my benefits because I am now "okay" to return to work, which is not true. I even lift a frying fan!



For benefits to continue, Bailey has to provide evidence to meet the eligibility criteria. One participant reported that accessing the tests is expensive; therefore, not feasible for someone recovering from an injury while simultaneously unemployed. This is a cause for concern as insurance status may be preventing survivors with persistent symptoms from receiving appropriate diagnoses. These data are consistent with Colantonio et al.'s (2010) study, revealing that insurance companies delayed allocating funding while focusing on the eligibility process. The study further revealed that the delay in adjudicating eligibility might negatively affect the individual due to the length of time to decide on the survivors' claim.

*Mired in eligibility morass*

According to the 2014 report titled *Mapping Connections: An Understanding of Neurological Conditions in Canada* (Neurological Health Charities Canada [NHCC] and Public Health Agency of Canada [PHAC], 2014), a quarter of adult Canadians living with a neurological condition such as brain injury, brain tumour, and stroke were permanently incapable of working. This report's findings are consistent with the current study's findings showing that most participants are unemployed and rely on disability benefits from EI-A and CPP-Disability. However, there was a consensus from all participants that the process of applying for benefits through social assistance, disability benefits through federal or provincial, and privately funded services were filled with struggles to get approval. Despite a medical history of trauma and injury, seven out of fifteen participants did not qualify for disability benefits under the Employment and Income Assistance program disability category and CPP disability benefits. Those who did not qualify were forced to resume pre-injury employment and/or access non-disability social assistance through the province.

The majority of the participants talked about the complexity of accessing services based on eligibility criteria. For example, one participant's experience originated from two perspectives-- her experience as someone accessing services and a program manager accessing services for her clients. Despite her knowledge of the system, she could not obtain the services needed, not because she did not know where to find them, but because she was not eligible for the services available. For example, Dawn found the Community Stroke Care Services (CSCS)<sup>4</sup>

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<sup>4</sup> Community Stroke Care Service (CSCS) is a specialized home care program for people who have suffered a stroke and would benefit from community re-engagement. The CSCS team provides case coordination, home care support and rehabilitation services to clients with rehabilitation potential referred from the Riverview Hospital inpatient stroke program (WRHA, n.d.).

program for stroke survivors through the WRHA. However, Dawn did not qualify because a stroke did not cause her brain injury.

Lots of things are not covered appropriately. Like you can't buy your way into the community stroke program, you can't do this, you can't do that. Well, I just want to have, you know. I actually really want to have some kind of testing, some actual brain testing.

Each brain injury is unique, and the impacts are also similarly diverse. Some people make a good recovery, while others are left with ongoing, invisible difficulties. Furthermore, difficulties in articulating the same services and supports needed, coupled with the hidden nature of the disability, make it even more challenging to meet eligibility criteria.

Participants narrated their frustration over accessing social care services. While there is no doubt that social services, such as Manitoba's Employment and Income Assistance (EIA), recognize brain injury as a disability, accessing support and recognition of such disability depends on healthcare practitioners' medical evidence. Adam had to book an appointment with his GP on several occasions to fill out the forms for the EIA for People with Disabilities program.

So, we present that to EIA, and they got rejected. He [the doctor] did write each of these requests on a separate medical slip of paper, and they were on the same slip of paper. And so I go back to him, and I tell him that. He just writes them all on the same, and gives it to me and doesn't even just like refuses to do it on separate because he is mad at them, and he is taking it out on me. Does this make sense? So, it is just a continual struggle for someone that would find this difficult if they were completely healthy, and I just find it overwhelming and crushing.

While Adam had support from his GP, Natalie's GP refused to endorse her medical form. Natalie shared her issues with applying for EI-A Disability program as follows:

I had many issues when I went on EIA a couple of years ago—because my doctor doesn't do not want me to go on disability – I might not be able to get work when I found a job. My GP has been a bit frustrating and not accepting my word for it.... like giving all the right details. Social assistance was really difficult, and like whether or not getting a disability was hard. Uhm, I have not been able to get the disability tax credit.

Foucault used the metaphor “carceral archipelago” to describe the medicalized subjectivity from the exercise of power and expertise (Foucault as cited by Blackhawk, 2016) based on medical evidence. Using the medical gaze, the hidden truth of the body is never invisible but always immediately visible. For brain injury survivors seeking diagnoses, the

impairments' often-invisible nature leaves their account of their symptoms as not legitimate in the absence of available medical evidence.

In the process of qualifying for benefits, participants must provide proof that they are legitimately disabled. In the current study, Orlando had to bounce from one application to the next because he did not qualify despite having a traumatic brain injury.

Back in 2002, I was involved in a car accident while delivering parts for my work. I had scarring. I had this big strata valve installed in my head because of the accident I had at my work. And they [WCB] did not even acknowledge I had an injury at work. That is because when I went to the hospital, I was not unconscious. I was able to answer all the questions. So they did not think I had a concussion.

Not being able to access benefits from WCB, Orlando had difficulty maintaining employment due to ongoing headaches. However, even then, he could not obtain benefits through the Employment and Insurance program for people with disabilities because he looked “fine.” Orlando spoke of his experience as follows: “it’s hard to say I have a headache and then go there that I can’t go to work because I had a headache. Come on, man. They are not very helpful when you say that to them. They will say take Tylenol or Advil and go back to work. As far as medical aspects go, I do not look disabled”.

Orlando’s case and many other participants in this study further reify disability into measurable and visible. Those who suffer from an invisible impairment, such as brain injury, are automatically in disadvantaged positions. In Foucault’s terms, medicine’s anatomical atlas directs attention to certain structures, certain similarities, certain systems, and not others, in so doing forms a set of rules for reading the body and for making it intelligible” (Armstrong, 1995, p.394).

Eligibility requirements for insurance and compensation schemes encompass direct physical injuries. The data from the interviews revealed that the system, nonetheless, privileges the injury's visible and measurable aspects of injuries. In other words, the individual or their experience of illness and disability are not treated or compensated by the insurance/compensation apparatus, but by the standardized diagnostic codes that they are assigned to (Phillips, 2003). Eligibility for compensation, therefore, rests on the power of the medical doctors and other healthcare providers. Certifying an injury's legitimacy is an economically and socially powerful role for medical professionals (Duncan, 2010). Duncan (2010) posits that the clarity of the medical gaze for measuring and knowing the injured body

better than the injured person cemented the system of signs, which codified bodily loss with monetary gains. For injuries such as brain injuries that could present as an ambiguous condition, the sick role's legitimacy cannot be derived from physical injury alone. Medical evidence is still regarded as the scale against which disability is measured (Duncan, 2010).

### **Theme Two: Individual characteristics**

Individual characteristics are composed of predisposing factors, enabling factors, and need factors. In this study, individual predisposing factors are defined as characteristics of the individual pre-injury. This includes the survivor's demographics (gender, race, socio-economic status), location in the social structure, and health beliefs. On the other hand, individual enabling factors include geographic location and income. In this study, need is defined as the severity of the injury and the number of services the participants currently need.

According to Andersen's model (2008), personal or individual factors related to the service user impact his/her experiences of accessing care. The participants' race and culture, gender, and level of understanding based on their education have significance for their health and services. In the current study, the importance of gender, race, and socio-economic status were explored.

#### *Gender*

Although the literature shows that gender and race impact care access, this study's results revealed different conclusions. But upon closer inspection using a disability and social justice lens, it can be gleaned that power and privilege play a role in access to care more than race and gender.

There were more male participants than women in this study. All male participants did not see any gender differences in how service providers treated them. Nevertheless, two women have a unique example from their standpoint.

One female participant shared her experience on how her gender played a role in accessing care. She pointed to the systemic patriarchy applied to her case when her male doctor consciously chose a medication without considering her reproductive choice. To illustrate this example, Natalie was told by her male doctor that her seizure medication, Tegretol (an oral drug prescribed to prevent and control seizures), is known to cause infertility with prolonged use. Her doctor refused to prescribe her the medication for that reason, "I could take Tegretol but like I

shouldn't if I want to be pregnant. But I do not want to get pregnant, which means I can take it. But he did not listen to the fact that it was an option for me to take it".

Consistent with the literature, this study also reveals that patients and doctors of the same gender typically have more good communication in the treatment process. One participant reported that as a female, having a female doctor, she felt heard and respected, saying, "my new GP is a woman. I just feel that she understands me better than when I had a male doctor".

Gender also plays a role in how a participant's disability was perceived. In particular, the female participants, particularly the female participants in full full-time employment or managing family lives, seemed to experience more challenges than male participants. Furthermore, one participant felt that women with less visible physical disabilities find it challenging to acknowledge needing care. Both Dawn and Cor shared the same struggle when they were accessing disability benefits. In particular, Dawn discovered that asking for an extension of her disability benefits before going back to work was regarded as a way for her to get out of work. It is worth considering that these results are consistent with Hagg et al.'s (2018) finding, indicating gendered expectations and responsibilities for women.

They were cutting me off with a long term disability, and I had no financial support. I was in the long term, but they did not allow me to stay because I look fine. As a woman, they [insurance] think I was trying to get out of work. I worked my entire life; there is no time when I did not work full time. I do not understand. I feel that my needing a longer time to go back to work means that I was a woman who wanted to stay home.

In this study, men and women expressed different adaptations to their new normal. It was more difficult for women to balance the various aspects of their lives, especially concerning caring for their family members. For instance, one female participant commented that despite the difficulties that come with her brain injury, she is still the homemaker. She has to take care of her children and household. She shared:

I have three children. I could not get on the bed. And I have to see my kids. I could not remember my nine-year-old say, Mommy, can you make me eggs? Yeah, I could not even bend over. If I am running the water or go to the fountain, I have to have my earplugs because I have a deficiency. But I have to take care of my kids.

Conversely, unlike female participants, married or divorced male participants have partners or wives to take on both home and financial roles in the current study. After William's diagnosis and brain surgery, he had his ex-wife to advocate for his needs. He further explained,

“she [ex-wife] had to take on the role of work, taking care of a new-born baby and taking care of me all of a sudden. If I cannot drive, I was not working. I was all of her time”. The same can be said for Evan when he shared that “she [partner] takes care of me, I was homeless and I stayed with her because I cannot take care of myself, and I have no one in my life except her”.

A report conducted by the Canadian Institutes of Health Research (“Traumatic Brain Injury: Does Gender Matter,” n.d) supports these gendered expectations in access to services and recovery experiences, indicating the need to consider social factors such as gender roles in understanding experiences and outcomes after a brain injury.

### *Race*

There is a growing recognition of racial and economic disparities in healthcare access and outcomes (Halwani, 2004). Racial inequality in the health care context is often indirect and systemic (Advisory Committee on Population Health, 2004). However, most studies that have been conducted are in the context of hospitalization and in-patient rehabilitation. In this study, race was explored in terms of differential access to care in the community.

Findings revealed some differences in the extent to which different groups included in the sample perceived race as a factor affecting access to services. Furthermore, the interview data revealed that survivors who identify as Indigenous and visible minority did not see race as a factor in access to care. Participants felt that they were treated fairly because they receive precisely the same services as everybody else regardless of their race. One participant identified as Metis commented that service providers were “not aware of what culture I was, nor were they interested.” But often, discrimination in health care is indirect and systemic (Halwani, 2004). According to the Ontario Human Rights Commission ([ONHR], 2004, para 3), “indirect discrimination occurs when everybody, regardless of their cultural, religious, and linguistic background, received the same services”. Canada is a multiracial country; thus, equality of access is not ensured by uniformity (ONHR, n.d.). In Manitoba, 18% belong to the Indigenous population, and 18.3 % are immigrants (Shared Health, 2019, p. 5). Therefore, the delivery of culturally sensitive services that cater to ethnicity and races' diversity would constitute equitable access.

The same sentiment was voiced by another participant, who identifies as Muslim, that service providers respected his culture by treating him the same as everybody else. He explains, “the thing is back home, it is a brawl... a brawl, everybody is always mad. Even our own family,

they are all over us. But here in Canada, we are treated as heroes”. However, a colour-blind approach does not result in equal access (ONHR, 2004). For this participant whose family came to Canada as refugees, being treated the same as everyone else is a good thing.

Bur, a visible minority who migrated here when he was five years old, shared that “I feel good every time people always look at me like I was a white guy even if I was not born here. When my worker [service provider] tells me that I do not have an accent and am almost like, Canadian”. Although Bur finds this well-meaning interaction as a compliment, this example of racial microaggression is ambiguously disempowering racial minorities (Cruz et al., 2019). As defined, racial microaggression refers to “brief and subtle verbal/non-verbal denigrating messages directed towards ethnic and/or racial minorities that carry the weight of the offending party’s implicit bias” (Cruz et al., 2019, p. 2). In this case, when a white person says it, it implies that he/she was not expecting to hear a visible minority without an accent. Bur did not fit the ethnic stereotype, which makes the compliment a form of surprise. According to Cruz et al. (2019), racial microaggressions are especially harmful in healthcare settings because service providers hold power and authority over the individuals they care for.

According to Health Canada (2011), some ethnic groups face health risks stemming from a lack of access to culturally appropriate health care services. Furthermore, the current study also revealed no offering of culturally sensitive services to the survivors. For example, Indigenous health services were not offered to survivors who identify themselves as Indigenous people. This could be because service providers are not aware of these services. This finding is worth noting, especially since Manitoba has a large Indigenous population, which makes up 18% of the population, the highest of any province in Canada (Shared Health, 2020, slide 109). Bubbles, from Northern Manitoba, shared her experience as follows:

I asked to have a conversation with the Aboriginal Services program, and few people were surprised to task for it. The nurses have no idea how even to put that request. The services for Aboriginal services are phenomenal and very appropriate. But because I have done many asking things. I knew the program was there. And I utilized it before, whereas my roommate has no clue that the program existed, and the staff did not give them information. I think a lot of it is, and healthcare people just did not know.

Conversely, two participants perceived that their being White affects their access to services. For instance, Adam shared, “I think EI-A feels like I do not belong there. And I have taken other people there with me. And they, without me saying anything, observe the same thing

when they go. People have made comments that I am too rich to be here, based on no monetary thing based on whether I have my teeth; for example, you know what I mean”? Orlando and Evan expressed the same experience that social services are more accommodating to immigrants or Indigenous people than to someone who is seen as White.

It could be argued that for Indigenous people and people of colour (POC) survivors, these things happen to them remarkably often, which normalizes this kind of service interaction. Despite belonging to the same socioeconomic status, some survivors who identify themselves as white felt that access to services was not equal and fair. Orlando explained, “They [EIA] have programs for immigrants, newcomers, and Indigenous people but nothing for someone like, you know me, who is down on their luck. It is as if you are white. You should not even need to be there”.

Wetts and Willer (2018, p. 794) argue that “when whites perceived threats to their relative advantage in the racial status hierarchy, their resentment of minorities increases”. In the current study, participants did not express resentment, but their perception of service access was based on an assumption of superiority. Furthermore, Orlando’s perceived privilege leads him to think that social services programs primarily benefit racial minorities. Bobo (1999) argued that Blumer’s group position theory could explain perceived privilege. The theory claims that when there is an expectation from a racial/ethnic group (such as whites) of higher status, they expect greater access to economic, political, and social resources.

Interestingly, perceptions of racial privilege were unrelated to social, economic factors. The study's findings revealed that those who found that they were treated differently (white) were mostly from low-income status. Another participant felt that he had been ostracized, being white and accessing services in a homeless shelter. He described his experience as:

I know, from the neighbourhood I am from, and the address on my ID and, and where I grew up, there was no one from that environment here at all. And that is continual, you know, I, I'm just trying to keep to myself and not trouble anybody, not cause any problems. And the staff here can attest to that and never had the bad news or suspend me. But I will sit down at the table, and they will say, white people, you are the one who caused all the problems. The young people will say, chip in the same thing, and then when I talked to them later.

*Socio-economic status (SES)*



As previously discussed in this study, most participants were unemployed and receiving disability benefits or social assistance. Several studies in the U.S. have found that low SES is associated with poor healthcare access and worse outcomes. As discussed under theme one, differential access to services can be attributed to the funding system.

Participants reported that the services they received would have been different if they could afford the services, especially treatment services for brain injuries, such as physiotherapy, occupational therapy, chiropractic, and neuropsychological care. However, these services are mostly not covered by the province. For example, Adam shared that his relatives with monetary resources could access healthcare services more quickly. As he explained:

I mean, do you consider Canada to have universal health care? If I had lots of income, and would even draw on other people's money like family money, relatives and such do? They go down to Montana, go down to the states, and just pay for medical service because they are not receiving it here. Okay, so with income, I would just, I would go down to the Mayo Clinic, I would go and spend money on my health care because it is not happening

Across all interviews, participants reported their struggles between waiting on a long waiting list to access care or quick access by paying out of pocket for expenses. The participants' ability to afford out of pocket expenses depends on their access to insurance attached to employment, as the beneficiary of insurance paid for by spouse(s), or their financial standing. However, with most participants receiving disability benefits such as EI-A for people with disabilities and CPP-Disability, there is limited access to many professional services that are not covered by the provincial health care plans. One participant expressed her gratitude for non-profit organizations that help survivors find jobs, provide services, and advocate for resources they otherwise would not have known. One specific example given was yoga therapy for brain injury survivors, free of charge through a non-profit organization.

### *Employment*

For some, employment is more than earning an income and serves as a funding source for health benefits. While a job provides more than financial independence, participants view employment as a funding source through private insurance benefits. As Bailey shared, "You will have to pay for all your tests. I have to provide my own medical, so I cannot, I cannot take it any further because I cannot afford it".

On the other hand, since Dawn went back to work, she has been accessing counselling for her anxiety issues through the EAP (Employee Assistance Program). Loss of employment also means loss of income, which leads to mortgages not being paid. When the interview was conducted, Bailey had an “open house” to sell the house his family had to leave after 25 years.

We have a little coming in but living off saving. We will sell our house, lots of tears for my wife and daughter. We had to downsize, so we had to purge a lot of our stuff. I moved in with my in-laws. I applied for CPP disability.

As employment is a large determinant of socio-economic status, two participants tried to go back to work. Bailey, whose brain injury left him with memory issues and chronic fatigue, could not keep up with his job's high demand and stressful environment. While the employer made accommodations to restructure his position, it was no longer viable. On the other hand, Trace's return to work plans was not successfully implemented. She perceived that MPI's abrupt cessation of healthcare services impacted her recovery.

Dawn and Cor were able to resume their pre-injury employment. However, both participants were prematurely driven back to employment by their lack of choice when their long-term benefit insurance benefits were terminated. Cor, a single mother, had to go back amid the migraines and brain fog, “I was trying my best with kids and work. And I did not take time to heal because I [could not] afford it. I was living on my credit cards; you know I had to pay rent and have kids. I had no choice. But really, I had not healed”. Dawn, a government employee, was cut off from her employer's long-term disability and had no means to support herself. She revealed, “I am still paying off what I owed in 2017. I went to my line of credit. I have used all my credit cards for everything. And that is not like I took a trip; I did not do anything”.

Financial constraints resulting from loss of employment/lack of employment impacted survivors' lives and made it more challenging to seek services. This inadvertently affected the participants' mental health and wellbeing, but quick access to psychological services was not readily available. Even with no income at that time, Dawn paid for the needed services but soon realized that it was not sustainable to continue.

And I went to a therapist who was \$180, which I had to pay because I had anxiety that I was trying to deal with it. It was also a huge change in my life when you had a giant medical incident, and so I went and paid for it because I was not feeling like myself.

Adam, who had been homeless after an assault, was struggling with his mental health and needed therapy. But, a referral from a walk-in clinic means a long wait for a psychologist. According to the Mental Health Commission of Canada (as cited in Shared Health, 2019, slide 120), Manitoba has the lowest number of psychologists per 100,000 residents than other provinces with only 181 licensed psychologists. Adam spoke of his experience, “he’ll send me out to a therapist again, I have to pay for that myself. With no work right now. I mean, it feels like there’s no one who wants to take agency over this or, or deal with it”.

### **Theme Three: Perceived need**

Individual domain need factors are defined as the cause of access to health and social services. In the current study, need is defined as the severity of the injury and the number of turns the survivor currently needed at the interview time.

According to the report published by Selkirk Mental Health Centre (Government of Manitoba, 2017), provincial-funded brain injury services are available through inpatient rehabilitation and acute care through the Selkirk Mental Health Centre ABI program, Northern Regional Health Authority (NRHA) ABI residence, ActionMarguerite, Concordia Hospital’s Post-Acute Neuro Surgery Unit (PANSU) and Riverview Health Centre’s Neurology Rehab Stroke and ABI units. Community-based services are offered through specialized homecare service called Community Stroke Care Services and Manitoba Brain Injury Association (MBIA). However, except for MBIA, admission to these services is by referral and based mainly on the medical evidence of a moderate to severe injury at the point of admission (Government of Manitoba, 2017). In this study, only three (3) participants had accessed in-patient rehabilitation. Of those admitted to the hospital, most of them were discharged to their respective homes. It is also worth noting that the participants in this study had their ABI for at least two (2) years ago, which most medical professionals would deem “medically recovered.” According to most experts, the bulk of recovery happens in the first two years, with most survivors regaining their function pre-injury (Model Systems Knowledge Translation Centre [MSKTC], n.d.). Some participants had home care services when they were discharged from the hospital. Three of the participants had availed of the specialized home care program through Community Stroke Care Services during the first-year post-injury. This shows that the majority of the participants who

were not able to access in-patient rehab through hospitals had no community-based resources. To illustrate, Bubbles had the home care program to help her get back on her feet after the surgery:

I just had surgery last February 2020, and I have homecare twice a week to stand by for a shower because I do fall. And to help me cook or laundry sometimes.

#### *Unmet needs*

Each brain injury is a unique event with a unique set of effects. Nevertheless, it did appear that the common difficulties arising from brain injuries have broad consequences and wide-ranging sequelae, which adds complexity to access to care.

As discussed in Chapter 2, the need for care refers to the illness or condition variable in the behavioural model, which includes the individual's report of symptoms and illness (perceived need) and the service provider's diagnostic evaluation of illness and symptoms (evaluated). Participants reported receiving several services that were not enough to satisfy their needs. For example, social work services were often limited to admission to hospitals/inpatient rehabilitation. Cor and Dawn both had the same experience. To illustrate, Cor shared her experience as follows:

I don't remember if I had any. You can look at my files and see. But maybe when I was at the hospital. But I didn't have any encounters with social workers other than when I was at Seven Oaks. But as far as I can remember, that was the only time I had an encounter with social workers. One friend told me that I could access RDSP or the other one, disability tax credit. But I didn't know any of that.

Similarly, Dawn had the same experience. She explained, "I had a social worker while I was admitted, but afterwards, I did not get help from a social worker. I had the occupational therapist who acts as a social worker".

This study's results contradict the findings from the literature on the severity of the injury as a driving factor affecting health care utilization (Hodgkinson et al., 2000; High Jr. et al., 1995; Vangel et al., 2005). Participants in this study who had a catastrophic injury were able to secure admission to the hospital and in-patient rehabilitation, thus lessening the need for healthcare utilization post-injury. Interestingly, those who had an injury classified as a mild TBI or self-reported injury without hospitalizations sought more help regarding community care access. One can hypothesize that participants find the complexity of their condition and not severity as an indicator of perceived need.

According to Andersen (2008), the perceived need is vital for understanding the care-seeking process and adherence to medical regimens. Interview data from this study is consistent with Corrigan, Whiteneck & Mellick's (2004) findings that unmet perceived needs appeared to be associated with behavioural and psychosocial outcomes, such as employment and mental health services of brain injury survivors.

Table 9

*Participants service utilization in the past 12 months*

|  | All<br>(n=15)    | Winnipeg<br>(n= 8) | Rural<br>(n=2) | North<br>(n=2) | Homeless<br>(n=3) |
|--|------------------|--------------------|----------------|----------------|-------------------|
| <b>Medical and Rehabilitative Services</b> |                  |                    |                |                |                   |
| Primary Care                               | <b>15(100%)</b>  | 8(100%)            | 2<br>(100%)    | 2<br>(100%)    | 3 (100%)          |
| Neurologist/Neurosurgeon/other specialists | <b>9 (60%)</b>   | 7<br>(87.5%)       | 1(50%)         | 1 (50%)        | 0                 |
| Vision Services                            | <b>3 (20%)</b>   | 3(37%)             | 0              | 0              | 0                 |
| Addiction Services                         | <b>2( 13.3%)</b> | 1 (12%)            | 0              | 0              | 1(33%)            |
| <b>Alternative Therapy</b>                 |                  |                    |                |                |                   |
| (chiropractor, naturopathy)                | <b>4( 26.7%)</b> | 4 (50%)            | 0              | 0              | 0                 |
| Mental health Services                     | <b>2 (13%)</b>   | 1 (12%)            | 1 (50%)        | 0              | 0                 |
| Physiotherapy                              | <b>6 (40%)</b>   | 3 (37%)            | 1 (50%)        | 1(50%)         | 1(33%)            |
| Occupational Therapy                       | <b>3 (20%)</b>   | 2(25%)             | 0              | 1(50%)         | 0                 |
| Speech and Language therapy                | <b>3 (20%)</b>   | 0                  | 1(50%)         | 2(100%)        | 0                 |
| Nutritionist/Dietitian                     | <b>0</b>         | 0                  | 0              | 0              | 0                 |
| Emergency Room                             | <b>6(40%)</b>    | 2(25%)             | 1 (50%)        | 0              | 3(100%)           |
| Others: Telehealth                         | <b>3 (20%)</b>   | 0                  | 1(50%)         | 2(100%)        | 0                 |
| <b>Social Services</b>                     |                  |                    |                |                |                   |
| Case management                            | <b>5 (33.3%)</b> | 3(37%)             | 1(50%)         | 0              | 1(33%)            |

|                                  |                  |        |        |         |         |
|----------------------------------|------------------|--------|--------|---------|---------|
| Behavioural Support Services     | <b>0</b>         | 0      | 0      | 0       | 0       |
| Assistive Technology Services    | <b>0</b>         | 0      | 0      | 0       | 0       |
| Medical Equipment Services       | <b>0</b>         | 0      | 0      | 0       | 0       |
| Respite Care/Homecare            | <b>2 (13%)</b>   | 0      | 0      | 2(100%) | 0       |
| Social Work Services             | <b>1 (6.7%)</b>  | 0      | 1(50%) | 0       | 0       |
| Counselling Services/Therapy     | <b>4 (26.7%)</b> | 3(37%) | 1(50%) | 0       | 0       |
| Transportation Services          | <b>0</b>         | 0      | 0      | 0       | 0       |
| Housing Assistance               | <b>4(26.7%)</b>  | 1(12%) | 0      | 0       | 3(100%) |
| Financial Management Assistance  | <b>1(6.7%)</b>   | 0      | 1(50%) | 0       | 0       |
| Vocational/Employment Assistance | <b>5 (33.3%)</b> | 2(25%) | 1(50%) | 0       | 2(67%)  |
| Others: _____                    |                  |        |        |         |         |

*Note.* \* indicates that services were accessed at different locations (Winnipeg or Selkirk, MB).

A quantitative service utilization questionnaire was administered to the participants before the interview. All of the participants reported having accessed healthcare and/or social services. However, all participants from the homeless population identified the emergency department as their usual source of care.

Results highlighted varied responses in terms of service use. The majority of the participants had accessed a neurologist and/or brain injury specialist. However, it is interesting to note that these participants all came from Winnipeg but did not include the homeless population. Out of 15 participants, two had accessed addiction services. Both of these participants were either homeless at the time of completing the survey or had been homeless at one point during their recovery. While alternative therapy is mostly not covered by insurance or income support programs after a certain period (12 visits per calendar year, excluding X-rays (“Manitoba EIA Health Benefits Summary,” 2014), four (4) out of fifteen (15) participants accessed these services by paying out of pocket.

Conversely, despite the breadth of literature on mental health issues and brain injury, only two (2) out of fifteen (15) participants accessed mental health services. This could be because, generally, the supply of mental health services is insufficient (Shared Health, 2019, slide 120), more so with the current study’s participants whose mental health issues do not fall under a major psychiatric disorder. According to the Winnipeg Regional Health Authority

([WRHA], n.d.), mental health services are provided through hospital-based services and community-based services. For hospital-based services, the focus is on psychological illnesses that require treatment. Alternatively, community-based services are offered through community mental health workers or shared counsellors (outside Winnipeg). However, only those diagnosed with a major psychiatric disorder are eligible for the service unless the ABI survivor is under the Public Guardian and Trustee of Manitoba<sup>8</sup>.

Physical rehabilitation such as physiotherapy, occupational therapy, and speech therapy was not utilized as much as the literature suggests (Jourdan, 2015; Hodgkinson et al., 2002; Hunt et al., 2016). This could be because most participants, albeit with reasonably recent injuries, did not experience physical issues as much as cognitive and behavioural issues. On the other hand, participants from outside Winnipeg could access rehabilitation services by travelling to Winnipeg or remotely through MBTeleHealth<sup>9</sup> services.

Concerning social services utilization, most participants have not had any case managers or caseworkers except those working with their compensation and insurance cases. Researchers examining case management services for people with brain injury reported positive outcomes in functional competence, independence, and social networking (Baptiste et al., 2015). Case management services are offered in-facility or through privately funded organizations (“Adult Mental Health and Acquired Brain Injury Services Map,” 2017). Although local brain injury organizations provide case management and advocacy services through the Manitoba Brain Injury Association (MBIA), survivors who have accessed services through MBIA were not part of this study.

All of the homeless survivors accessed and continued to access housing services. Regarding vocational and employment services, unemployed participants on EIA were accessing vocational and employment services through several non-profit agencies offering these services.

The impact that brain injury has on the participant’s cognitive functioning and behaviour make accessing care even more problematic. This is due to the lack of knowledge and understanding from the service providers and the survivors’ inability to communicate their

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<sup>8</sup> The Public Guardian and Trustee of Manitoba is a provincial government Special Operating Agency that manages and protects the affairs of Manitobans who are unable to do so themselves and have no one else willing or able to act (Government of Manitoba, n.d.).

<sup>9</sup> MBTelehealth is a service provided to Manitobans living outside of Winnipeg to access health services through the use of technologies (MBTelehealth, 2020).

health and social needs. Natalie, who described herself as reasonably intelligent and finished two university degrees before and after her injury, often finds herself in the same dilemma as she shared, “I found out that sometimes, it is difficult for me to remember and hard to communicate what I wanted and feel that I was heard”.

Participants also highlighted that the struggles of finding services worsened the psychological symptoms associated with brain injury. What may normally be easier for a non-brain injured patient to endure, such as completing a form, cancelling and remembering appointments, is taxing to do for someone battling with myriad issues that prevent one from doing her or his part of attending to her or his care. Participants are adjusting to a new normal, and this is challenging enough. However, now there is an added burden of the emergence of a new disease or medical issue that was not present before the injury. It is worth noting that most participants reported having been diagnosed with a secondary medical problem after they had sustained their brain injury. Bailey, Orlando, and Kaye experienced the added burden of medical issues unrelated to their brain injury. To illustrate, Orlando and Bailey developed hypertension post-injury. Bailey stated:

I went in for blood work, okay? That would have been a week ago. In the last six or seven months, things have taken a turn for me. My liver, all of a sudden, I have the liver of an alcoholic. I don't drink, my cholesterol, my blood pressures have always been good. And my blood pressure has started to climb. Now that could be partially because of the stress of losing the house and stuff, right. This is something new after the accident.

According to Schultz and Bellamkonda (2016), medical complications and issues after a brain injury are common and should be considered by doctors. Common medical complications include seizures, hypertension, hyperactivity, hydrocephalus, agitation, neuroendocrine dysfunction, and cranial nerve dysfunction. For Bailey, this complicates his access to services as the new medical problem is treated separately from his brain injury.

Sherry (2006, p.180) claimed, “brain injury is not just a cognitive experience; it is an embodied one”. For survivors, brain injury brought significant changes in their lives, altering their entire being and making them into entirely new people. The majority of the survivors acknowledged that they are now in a different version of themselves than before the injury. However, survivors framed these changes as their new normal as they continually adapt and cope with the ongoing yet permanent symptoms.



Some participants stated that in accepting and adjusting to the changes resulting from the brain injury, they have developed and learned coping and adaptive strategies in response to their unmet needs. The majority of the participants reported poor memory that led to forgetting appointments or verifying if medicines were taken. For Bailey, he has to bring his wife or daughter to appointments. He explained:

And then I try and explain things to her [wife] as soon as I get out. Because it does not take very long, like even this conversation, most of all, we said, in a few days, I will not remember.

Natalie, Kaye, and Dawn use their cellphones as memory aids to cope with short-term memory loss. They reported using their cellphones to schedule appointments and reminders.

The majority of the participants identified fatigue as a deficit from brain injury. Trace had to adjust her daily schedule to survive, managing fatigue. For instance, when she attended a neuropsychological assessment for a half-day, she did not do anything for the next three days. Adams and Dahdah (2016) state that brain injury survivors experience fatigue more often than non-brain injured people because they have less cognitive energy used the energy faster, and had more difficulty renewing that energy through rest and sleep. In the same way, Dawn had to cope with fatigue by reducing sensory stimuli. She explained:

I was asked if I could have an office with a door where I could close where I could turn off the lights and put the lamp.

According to Heinemann et al. (2002), the high prevalence of unmet emotional, cognitive, and social needs is consistent with other studies documenting severe behavioural problems that can persist even when physical impairment is minimal. Participants who were discharged from in-patient rehabilitation services began to realize that they may have developed deficits that may be permanent. It appears that many participants came to this realization when they returned to their respective homes and communities. Cor shared that she thought she had recovered during inpatient rehabilitation because the service providers were sending her home. She explained:

I wanted, they should've, like way back when I got out. They should have some kind of counselling or support or something because you are out of it. To me, if something that severe, they should have a program to prepare us.

While some participants were able to learn strategies, Orlando self-medicated his chronic headaches and mood swings, which resulted in ketamine addiction. This participant recounted that his addiction led to criminal charges, which left him unable to find employment. As a result, he was homeless at some point before acquiring his second brain injury.

I didn't have any income. I stayed with a friend for a month. Then I got my income tax, and that kind of help me. I stayed with my friend. I gave my friend most of my money. He was really good.

There are so many nuances to this situation. However, one can surmise that the addiction or the homelessness was partly because a brain injury occurred, and services and support were not readily available to mitigate the risk.

Kumar (2014, slide 6) found that the top three unmet needs were (1) improving memory and problem solving, (2) managing stress and emotional upsets, (3) improving vocational skills at the pre-injury level. In this study, notwithstanding the four (4) participants who could access counselling services through private funding or out of pocket expenses, the majority had no access to government-funded behavioural and counselling services.

Although the medical model illuminated the long-term consequences of brain injury, such as the physical, cognitive, and behavioural effects, it also cemented medical experts' role in determining brain injury survivors' needs. The broader social aspects of brain injury such as loss of friends, social isolation, loneliness and family problems are not well supported with the absence of mental health and social support. Kreutzer et al. (2002) suggested that a more holistic health approach to ABI is necessary to treat the person solely based on symptoms. The current study's findings support the previous research on the need for a greater focus on survivors' social and community needs (WHO, 2004). Furthermore, participants reported a perceived lack of education on how to manage their changed lives. Natalie believes that "I think part of that is them knowing what's out there because it is exhausting to find it out yourself". On the other hand, John Wayne shared:

They didn't offer anything, we. We were not aware of what's there unless you do the work yourself. My children help me find anything if they had the time, which they don't.

In addition, participants noted that their unmet needs would be improved if there were education and coordination in the system. Orlando suggested:

GPs don't know, basically somehow. They have to coordinate. At least have a website doctors have somewhere they can look for whatever services are available.

Finally, the availability of funding was endorsed by participants to help them to meet their needs. In particular, Bubbles argued:

I would have probably flown down instead of taking a 10-12 hours' bus ride. I always ask my cardiologist and neurologist when they are coming to Thompson to provide services. It would be much cheaper.

#### **Theme Four: Power and Knowledge Nexus**

In this study, the power and knowledge nexus are defined in Foucauldian terms (Foucault as cited in Tremain, 2005). In this study, power and knowledge refer to the service user-provider power distribution and knowledge translation/production about brain injury-related information. Interpersonal encounters with the service providers were assessed as this is the site where bio-powers are exercised.

##### *Arbiter of knowledge*

The health and social care systems are composed of individuals who needed care and professionals who supplied the care and a network of structured interactions. In this study, service providers, specifically healthcare practitioners, were regarded as arbiters of knowledge. There is an inherent power inholding these positions concerning access to care.

Several participants reported that doctors are regarded as experts on brain injury. Hence, a refusal to validate a survivor's diagnosis leaves the survivor powerless. As previously stated in the literature, biomedical evidence is treated as the gold standard in judging what is considered to be acceptable knowledge. Service providers, such as healthcare practitioners and social service workers, are regarded as crucial in defining what constitutes acceptable knowledge. Ultimately, expert knowledge gives legitimacy to a service provider's status. Orlando, who received a proper diagnosis from his neurosurgeon, shared, "I hope my neurosurgeon has the most power. But as far as being diagnosed, and knowing what I need, I hope he has more power".

The above reflects a reliance on what is conceived of as expert knowledge in fulfilling the need for certainty, and ultimately, guidance in decision making. Expert knowledge encourages a power differential to provide a compelling reason for accepting specialists or experts' advice. Participants reported that while they recognized that they have power over their care, they also lack specialized knowledge about brain injury and therefore have no reason to

base their decisions on their knowledge. The professionals possessed technical knowledge on brain injury and therefore were regarded as authorities over their condition.

However, while medical evidence is judged as more accurate, it disadvantages the survivors' subjective lived experiences. As Bailey shared:

But he [the doctor] says that we have to go by those reports based on the tests and the experts. And so, the last time I got a little upset in his room, and I said, Look, I do not care what these things say, something happening here. And somebody needs to take notice.

Sherry (2006) argues that the medical model discounts brain injury survivors' lived experiences and gives them little opportunity to contribute to the analysis of their situation. In the current study, participants were often placed in a position where they had to fight to have recognition of their condition or relinquish control over decisions that would affect their lives. Although some of the impairments that result from a brain injury cannot be improved by medical intervention, physicians and other medical service providers still retain power over their role as gatekeepers for assistance with housing, employment, vocational rehabilitation and disability benefits (Sherry, 2006). For example, Natalie was denied access to a vocational rehabilitation program because her GP refused to endorse her medical form. She stated:

I went to my doctor about a week ago, my GP. Despite being my GP for the past six years, she does not have a rundown of my AVM symptoms. She wants me to see an OT instead because she will not sign the form.

While Bailey lost his WCB benefits and job because his GP did not think he has a brain injury. He explained:

If they had listened to me and researched more on what my experience was, what my accident was, I think things would have been better for me. I would not be three and a half years, three years later losing my house. Maybe I would. I do not know. It would have been different, but I think yeah, I think the process to get to this point would have been different. Yeah, like everybody says, Yeah, you have got something going on. You have got a little bit of this. You have got a little bit of that. Somebody get on the page here and figure this out. Like someone takes the time to someone, take ownership of the patient and figure out what he needs is that is the biggest thing.

Often the knowledge an individual receives is fragmented. Participants reported receiving conflicting information regarding their injury. This could be because brain injury symptoms are

manifested in wide and varied ways, as suggested by one participant diagnosed with a brain tumour.

And I remember that when I was first diagnosed, the doctor said, I do not know which doctor if he was a cancer doctor or not. He said I would make a full recovery, and then I went to HSC and saw another doctor and the surgeon, and they had a very different answer for me. And the doctor said they were going to do one month of chemoradiation. And uhm... 6 months of chemo after that and see how it goes. They are treating stage 4 cancer. But I have technically stage 3 astrocytoma because I was so young and because the markers came back-- they are not sure if it was stage 3 or stage 4.

With the advent of technology and the availability of information at our fingertips, information from experts is now competing with publicly available information. The majority of participants have access to the internet and have been informed through their own “research”.

I am like, always like, is it a brain injury? Canadian brain injury website, and here are three boxes, and I have cut and pasted them. And that is what I have in mind? Yeah, you know, the first bubble has, you know, the headaches and dizziness, nauseousness [sic] gap, those are all fatigue. Those are all things that I deal with daily.

Foucault's concept of the medical gaze, defined as the “act of seeing”, is central to how the body is assessed within the context of normality (Sherry, 2006, p. 48). It is a form of social control whereby the body is separated from the person, analyzed, probed, and examined (Foucault as cited in Blackhawk, 2016). Foucault traced the history of medical knowledge through the medical gaze, which legitimizes medicine's power to make a disease/impairment knowable (Hughes, 2017). This establishes the distinction between normal and pathological, which sets the dualistic logic that invalidates the impaired people on the grounds of bodily difference from a medically fabricated norm (Hughes, 2017). Furthermore, Hughes (2017) added that “this regime of truth made it possible to ‘see’ impairment and to ‘say’ disability as a physical or mental deficit” (p.83). As Foucault reiterates, “the invention of the medical gaze brought about a shift in understanding, what was once concealed became revealed through the illuminating power of the gaze, and in so doing, the medical knowledge was considered free from distortion as it brought unprejudiced truth to light” (Foucault as cited in Blackhawk, 2016, p.3). One can argue that cognitive impairments such as brain injury that are not physically visible outside of this realm are not considered a disability.

Yeah. And it is like, I am not trying to convince anybody. I know what I have got here. I just want somebody to explain this stuff, explain it, understand it, like, take the initiative

to go and say, hey, maybe there is something more here than what is in the textbook that I know about.

### *Interaction with Service Providers*

In this study, service providers are situated as experts. In terms of diagnosis and prognosis of their brain injury, participants look for medical practitioners to provide them with the comfort of answers. However, they are often met with uncertainty concerning the trajectory of their recovery. This uncertainty is intensified when a professional they deem as an expert does not have the answers they hoped. For instance, Cor has been subjected to numerous MRIs for the last 18 years, but none of the doctors tell her anything about the MRI results. She shared, “one doctor telling me you are gonna have seizures. But they could not tell me what is exactly on my file. So, now I want to talk to a neurosurgeon who actually can read the file”.

Service provider interaction is essential in gaining access to care. However, knowledge construction affects this relationship. Survivors construct their knowledge based on their understanding of their condition, while healthcare professionals based their knowledge on their education and professional experience.

This is something that I brought up at St. Boniface with the nurses and anybody who would listen to me. I said, you guys are talking your casework back in that little room. The doctors and the physician assistant and the nurses and sometimes the health care aides. Yeah. And you are deciding things. You are making the deal. And you are not even talking to us about it. Like, what are our thoughts? You know, or am I even allowed to do this because it might be culturally wrong for me or spiritually wrong, or you know, and to this day hold to the day that they discharged me. I know the nurses and the health care aides were making more of an effort to come and talk with me. But nobody else was. When you have those team meetings, I should be in a team meeting to discuss me.

Bailey expressed his frustration over his GP, who would not acknowledge his brain injury based on his account. As Bailey shared, “when I went to see my neurologist, I brought him a list of the things I was experiencing because of my memory loss. I always forget the details. So, I brought him a copy of the report about the electrocution and brain injury so that he would have something to reference”. Despite all the research evidence that electrocution can cause brain injury coupled with self-reported symptoms presented to his doctor, Bailey's doctor refused to believe his symptoms are real.

And he wrote back to my physician, saying that I was trying to convince him that I had something wrong with me. Yeah. And it is like, I am not trying to convince anybody. I

know what I have got here. I just want somebody to explain this stuff, explain it and understand it, like, take the initiative to go and say, hey, maybe there is something more here than what is in the textbook that I know about.

Canada's universal health care positions, the general practitioner (family physician) as the gatekeeper of services. Diagnosis and referral are primarily affected by the service provider-service user relationship. The majority of participants think that their GP is doing them a disservice by not incorporating their voice into their diagnosis:

And my second GP was like. I think you should probably take aspirin because you had a stroke. I am like I had a hemorrhage; I do not think I should thin my blood with aspirin.

Participants considered their GPs diagnostic skills, specifically for brain injury, as inadequate. This causes much frustration for participants who just want answers to their medical issues. Dawn shared her experience as follows:

They are very unwilling in any way to go out on, to say that that could be normal for a brain injury, so you know. Like when I had these panic attacks, and I wondered why I had them, all I needed was someone to say that it is normal for a brain injury. But all they keep saying was this. I know nothing about brain injury. I know nothing.

Participants reported that their GPs often told them that nothing was wrong with them and nothing can be done. They felt that these general practitioners often made inappropriate changes to their medication and ordered unnecessary tests. Her GP told Kaye that her sense of smell would come back, which contradicts what the neurologist said "the neurologist he sends me to say that I would never be able to smell again for the rest of my life. So, it is kind of a conflict of bedside manner --him trying to make me feel better but at the same time giving me false hope".

On the other hand, Dawn and Cor, who has been requesting a referral for a consultation with a neurologist, kept getting CT scans instead. Cor spoke of her experience

They keep doing them, but then I said, look, I don't want to do any more CT scans if I don't get to see a neurologist after. As soon as they see the same damage, they will tell me it was old news, same damage, and nothing can be done. Luckily, this tech at Misericordia insists, and I guess she must have written something on the file because when I went back, all of a sudden, my doctor was like, "oh, I am going to refer you." There is just no connection. I get it. The system is busy. But it also takes 18 years for them to refer me.

On the other hand, several participants expressed that they felt like their doctors were not treating them equally by ignoring their symptoms and medical issues and refusing to address their concerns. Natalie expressed her lack of options and that her doctor just chose her medical treatments. Although she trusts her neurologist's medical knowledge, she believes that it did not consider her preferences, such as wanting therapy instead of antidepressant medications. As Natalie described:

I am usually not given a lot of choices. Yeah, I mean, the biggest choice I have been given is whether I would get a pacemaker or not. They left that up to me. But when it comes to medication and treatment, I sometimes find my doctor is good at offering me what I want but sometimes prescribing me something that I do not necessarily want, like antidepressants.

Participants also described their interaction with their physiotherapist. Kaye shared her experience while in an in-patient rehabilitation centre:

When I was doing physio, I would be so angry at the lady teaching me. She would try to tell me stuff. And I told my mom that "she talked to me like I am stupid. She talked to me like I am not all there. But she does not think I do not get it, but I do. I do not like it when people treat me as stupid, but I know I am not. But sometimes they treat you like I am not a normal person.

Although brain injury affects cognitive function, Natalie lamented that she felt stupid listening to her doctors because of her memory issues. These feelings are sometimes confirmed by the way her service providers treat her:

There were a couple of tests with my neurologist, where he assumed that I had not done it before or treated me like I did not understand what was happening. It was more of those vision testing things where they over-explain it to me like I have not done it before. That was kind of condescending.

Despite the apparent importance of a primary care provider's diagnostic and care skills, most of the descriptions of a good experience with service providers were concerned with interpersonal skills. Participants reported that their service providers' knowledge and experience were highly valued, but so were attitudes and interpersonal skills. The personal connection in the service provider relationship was emphasized, particularly concerning attitudes toward the participants. For instance, Dawn's occupational therapist at the hospital went over and above her duties by helping her learn coping strategies even after she was discharged. Dawn explained,



“My GP was terrible, but I have a good experience with the occupational therapist. She really helped me out at HSC. She was really wonderful”.

For some participants, good experiences with a service provider are defined by their responsiveness to their concerns, preferences, and questions. One participant describes her experience in finally being served by a GP who knows how to listen to her:

It feels like they are in the same room as you. Like they are not just using their brains, I am guilty of that all the time. But sometimes, when you interact with doctors or some brilliant people, they are here [pointing to head], and they do not always feel like they are here [pointing to chest]. I felt like she is in the same room as me.

Orlando echoed this same feeling of being responded to concerning his experience with service providers:

I lucked out in the neurosurgeon department. When I asked something urgent when I was talking to him about the cyst getting bigger, he told me, so wait there, and I will come. I forgot that he said that. But he did take a moment and talked to me after seeing the MRI.

Participants find it comforting when service providers take extra time to explain and understand their injury. Cor had horrible experiences with her previous GPs. She finally found a physiotherapist who did more than her GP could offer. She spoke of her positive experience as “You know what, she got it. She listened. She knows the whole system, and she said it is not coordinated. I was like, where have you been? I wish I knew you 18 years ago”.

Similarly, William found good support and an ally from his social worker, “my good experience is with my social worker, she's very supportive, she came to the apartment when I was sick obviously, talk on the phone”. William claimed that his social worker “knows how to connect me to the right resources available”.

### **Theme Five: Language**

In this study, the construct language refers to the discourses surrounding disability. The language used (disability) shapes power relations and knowledge production. Thus, it continues to influence how society has and defines, understands, and responds to disability. Disability remains focused on the medical perspective and impairment-related factors as clinical indicators that legitimate the need for treatment while neglecting to address the underlying structures and processes that undermine health.

In Moss and Dyck's (2002) study, they found that people with invisible disabilities such as brain injury are in the "in-between" hegemonic discourses. They are left with a disability that is problematic and alters their lives but is not "disabled" enough for casual observers to identify them as disabled.

Participants in the current study are no strangers to these discourses. When symptoms and disabilities are invisible, entry into the system through diagnosis becomes challenging. Furthermore, the participants noted that they do not fit into the mould of service provision. For the most part, brain injury is regarded as outside of structures and common understandings of service providers. Trace has been told that her condition is temporary, but two (2) years later, she continues to have the same deficits that could only come from a brain injury. She clarified:

But for so long, we were told it wasn't a brain injury. That it is only a whiplash. Then you don't have that proper understanding. And that's the biggest part, that's my biggest frustration.

After 18 years, Cor still believes that advocacy and education should have been offered to her family, knowing that those in positions of authority and power are ignorant of the condition.

My dad and mom were really good. But they had no education. There should be some kind of education for families in hospitals, for families and friends. A one-hour thing, the reality is they may look good on the outside. Society, in general, they do not discuss it.

The biomedical model has long dominated the health and social care systems. The definition of disability is based entirely on medical evidence focused on physical symptoms, and less consideration is placed on social factors (Sherry, 2006). This model's superiority translates to other areas, especially in defining what constitutes a disability, more specifically, brain injury.

### *Diagnosis*

Diagnosis is an essential aspect of accessing not only healthcare but also social services. The first entry to the system consists of convincing service providers that something is wrong with the individual. Gaining access to any kind of service is initiated by the general practitioners (GP) or family physicians who act as the gatekeeper for specialist services. However, Colantonio et al.'s (2010) study revealed that misdiagnosis and delayed ABI diagnosis are shared among service providers. They attribute this to service providers' lack of training and experience in differentiating between mental illness symptoms and symptoms of brain injury. Furthermore, the

study reported that diagnosis affects patients' access to rehabilitation and long-term follow-ups (Colantonio et al., 2010).

Bailey, who was seen by the Emergency Department (ED) physician after being electrocuted and “looked” unscathed, was never given any tests. He said, “...they didn't really even know...they test for a heart attack [diagnostic tests] and stuff like that and, and gave me Tylenol for my headache, and then sent me out the door after I was there for a few hours”. Without any diagnostic tests related to the brain, such as CT or MRI scans, there was no medical evidence supporting that he had some neurological damage related to electrocution.

Physicians have the power to provide diagnoses, yet they rely heavily on the body's materiality and often doubted any experiences of being unwell (Moss and Dyck, 2002). In Bailey's case, he could not articulate his bodily experience in a way that would make sense to the biomedical discourse; thus, there was no proper diagnosis of his condition. He expounded, “I was out of it, but I was alert and wasn't unconscious. After the EEG, I was good to go”. This supports Colantonio et al.'s (2010) findings that diagnosis is complicated by latent manifestations of symptoms months or even years after the injury.

At the time of their injury, most participants reported that something “wasn't right” to their service provider. Despite multiple and repeated utterances, all these complaints fell on deaf ears in the absence of visible evidence. Orlando, who had a grand mal seizure and brain bleed after seven years of complaining to his doctor that something was wrong, spoke of his experience:

I had headaches like you couldn't believe. Before I had my surgery, I had a cyst developed because of my accident. I had the worst headache; I want to die. It was so terrible, and it did not go away for months. Talking to my doctor, my doctor tells me to take Advil. Take an Advil. I took 10 Advil once, and it didn't do anything.

This speaks volumes on what kind of knowledge was privileged. The weight that service providers put on medical evidence over the participant's self-reported symptoms also affects diagnosis. This places more emphasis, and ultimately power, on what experts believe to be the legitimate basis of the survivors' condition instead of their knowledge of their condition. In the same vein, one participant shared, “I think if they had listened to me and researched more on what my experience was, what my accident was, I think things would have been better for me”.

Cor, who had a previous injury from a horse-riding accident, had another concussion two years ago. But, because the CT scan showed the previous damage 18 years ago, the emergency department (ED) did not do anything about it. She explained:

I fell again two years ago, smacked my head and was out, and I drove myself to Victoria [hospital], which I shouldn't have. They [ER doctor and nurse] asked me why I drove. But all I knew; my brain was telling me to go to the hospital instead of calling 911. They did a CT [scan], but then again, they said you have previous damage. I ended up having a concussion. They did not do anything. They misdiagnosed me. I tore my shoulder, tore my rotary, and had a concussion, but they had me drive home.

Meanwhile, I had a concussion then. I was totally out of it for a week. They misdiagnosed me because of my previous damage. I was supposed to be on an airplane to Las Vegas. I had to cancel the trip, lost a bit of money.

While Bailey, Orlando, and Cor's experience happened in different hospitals and circumstances, a study conducted in three Canadian emergency departments shows that one in six patients with concussion signs and symptoms were misdiagnosed in the ED (Rowe et al., 2018). The authors posit that misdiagnosis is related to the injury mechanism, length of stay, and enrolment site. Furthermore, patients without a diagnosis were less likely to receive a recommendation to follow-up with their GP (Rowe et al., 2018).

As previously discussed, each brain injury is unique, and without proper diagnostic tools, it will even be harder to determine the diagnosis. For instance, more than half of the participants did not receive a diagnosis of brain injury right away. Allan, who had undiagnosed injuries from the assault and a car accident, never received any treatment for his injuries. It did not help that Allan was living on the streets when this happened. He shared, "When I was beaten, I was unconscious, so the police took me to the hospital, but there was no follow up after that".

Misdiagnosis is another issue raised by the participants. Bur, who had been treated for a psychiatric issue for several years before a psychologist learned of his childhood brain injury, was grateful that "it is not all in his head". He said, "I went to a couple of doctors and psychiatrists. And then this one psychologist told me one time you should go and get a CT scan. She was doing the examinations on me. And then from there, she referred me to EI-A disability to access services".

According to Foucault (cited in Moss and Dyck, 2002), the experience of discourse is not grounded on words and ideas but by material practices that produce and reproduce specific meanings. Diagnosis is one practice rooted in biomedical discourse that provides legitimacy to

the survivor's symptoms and condition to be socially constructed as “ill”. Despite her medical history of brain arteriovenous malformation (AVM), Natalie's GP did not sign her medical requirement for disability benefits. She explained:

She wanted to see reports from my occupational therapist, even though she has seen updates from a bunch of specialists put together. She does not think or have the evidence to say that I have cognitive processing issues in vocational service.

In this case, medical evidence from an occupational therapist has more power than the participant's history and lived experience. As Moss and Dyck (2002) postulate, the power and legitimacy attached to biomedical knowledge become more legitimate because of the power attached to it through the practice of medicine, by insurance companies' reliance on the allocation of benefits, and in the workplace administration of accommodations.

*Disability versus Invisible Disability*

The invisible nature of brain injury tends to be overlooked by service providers and affects individuals' access to care. The medicalization of disability shapes how brain injury is understood and viewed not only by the public but also by service providers. The findings of this study revealed that the impact of brain injury is not a one-time event. The unique combination of cognitive, behavioural, and psychosocial consequences of brain injury adds to the complexity of diagnosis, treatment, and rehabilitation. On the other hand, participants' interview data showed that the changes that come with brain injury were not instantaneous, as some changes occur at the point of medical recovery. While brain injury survivors were aware that they were not the same person post-injury, the wide-ranging and broad array of long-term consequences is hardly understood. The long-term consequences and sequelae from the ABI were not immediately recognizable from the survivors' point of view. In the current study, data showed that brain injury survivors could not recognize some of their symptoms or make an informed decision on how to find access to services to treat it. Some of the symptoms are not objectively verifiable, making it even harder for survivors to articulate their needs. What is known, though, is the significant impact that brain injury has on their lives. Brain injury survivors' disabilities have left them with changes, and they have to keep on adapting day by day. The majority of the survivors have learned to adapt by using strategies to manage the impairments. However, the coping skills developed helped compensate for their deficits, while masking the true nature of the impairments, which inadvertently affect their access to care because they look “fine” and

“normal”. In Cor's case, it has been 18 years since her first injury, yet she still feels that something needs to be “fixed”.

It reminded me that it was so screwed up. And they don't educate the family either, or then I found out in general that it is very lonely afterwards. Because once you look okay, they do not know that it is all marbles in there.

Cor externalized her disability through discursive constructions of brain injury as something is wrong, but at the same time, there is an expectation of hope for improvement. She wants to gain control of power by asserting that the medical evidence from CT scans did not provide adequate answers as to what is wrong with her.

Participants also construct their disability according to a “survivor” discourse. There is a deep appreciation from the participants for their “second life”. However, these appreciations are filled with depth and tension over not having the kind of support and services they need to adapt to their new life. One of the participants had this to say:

As far as positive, I lived. You know what, wherever people are leaving, they were not ready for me yet, and I was here for my kids. They needed me. The negative is—the medical society in general or the medical system.

Sherry (2016) implies that the term “survivor” is empowering (p. 192). This discourse appeals to this population as it links to the hegemonic discourses around power and self-agency (Sherry, 2016). Bubbles, who had her first stroke six (6) years ago, had to restart her life again a few weeks before the current study's interview. She tearfully shared how she survived her second stroke:

A few weeks ago, okay. That is when February 13 [2020] is when I went into Emerge [emergency department] here [Northern Manitoba], and it was my heart racing hard. And they had to. I can't remember what the words called cardiovert, my heart they had to stop it and restart it. I died on the table, and I don't know how long they said they worked on me for over 40 minutes to get me to come around.

For brain injury survivors, a disability discourse is often accompanied by an invisibility discourse. Trace chronic fatigue is always misunderstood as she shared, “how can I convey that [brain injury] to people when they just see me as sitting around being lazy”? The invisibility discourse is associated with perceived stigmatization, which creates a position of disempowerment. As one participant shared, “brain injury is such a negative, negative stigma”.

Participants reported that the physical changes did not come as soon as they were diagnosed with a brain injury. They just woke up with one thing after another and realized that they do not function the same way as before. Dawn shared her experience as:

I was asked if I could have an office with a door where I could close or turn off the lights and put the lamp. Like today we are having a meeting, and I had to ask someone to stop eating next to me because I cannot hear. It's part of how I ended up.

This example points to the invisible disability discourses on brain injury, which contributes to the lack of understanding of the impairment's extent. As such, participants described that their brain injury's invisible nature leads to behavioural and personality changes attributed to their personality or the assumption of the absence of an injury.

In this study, participants identified more with their impairment than as a person with a disability. For example, Trace described some issues with which she deals, which are not improving as fast as possible.

So, I think it's been now at the two-year mark or approach where we discuss more as a family. I've got some friends that understand entirely. Like it doesn't bother me if it means that I can experience life. If you want to ask me questions, I'm happy to educate you. I still can't tolerate lights, and even the EMT understands that it's a brain issue. I kept asking myself, how do I get rid of [symptoms], or how does that change? And I don't have those answers yet.

However, it is interesting to note that there is an inherent power struggle for brain injury survivors to divulge and consequently embrace their newfound identity as someone living with a brain injury. While those who are employed recognize their deficits, they often hide that they have a disability. One participant shared, "I do not discuss it. Even years later, I tell people I had a critical accident. But they don't understand even those who know. As far as friends or anything, I do not discuss it [brain injury]".

There is ambivalence in how individuals embody their brain injury, whereby stark differences in acceptance emerged from those who are more educated and employed than those who have relinquished the idea of working again. Seven (7) participants were trying to return to work, but only two (2) out of 15 participants could continue their pre-injury employment. These two participants were both working at the management level and the ability to drive. Participants also reported having the support of their employers in accommodating some of the known deficits of brain injury such as sensory overload and cognitive fatigue. This supports the

literature findings (Birgit et al., 2016), stating the role of work modifications, employer support, and financial incentives as factors in a triumphant return to work.

One can argue that the government's legal definition influences this through policies that govern disability benefits whereby disability is tied to the person's employability and ability to contribute to society (Jongbloed, 2003). For instance, CPP defines disability as both “severe” and “prolonged”, and it must prevent you from being able to work at any job on a regular basis” (Government of Canada, n.d.). The transformations in state disability benefit programs and policies buttressed by the advent of neoliberal ideology re-asserts “ableness” as a necessary condition of citizenship and inclusion (Chouinard & Crooks, 2005).

The invisibility of brain injury makes it harder for participants to embrace the identity of someone who is disabled. Participants are confronted with disbelief for their struggles. It is perceived as having less difficulty than those with more visible physical disabilities. As Rose shared, “It is the difference between having a concussion and having a broken arm. People can go, oh look at that, you can't miss that”. Several participants described how in encountering service providers, they were met with disbelief when they sought help for their brain injury.

I remember seeing one doctor once before I saw him specifically about this after my car accident, and he kept trying to direct all of his questions towards addiction and stuff. I am just like; that's not why I am here.

The majority of participants strongly expressed the need for public education and awareness to the general public and service providers. As a brain injury survivor and social service provider, Dawn believes that medical professionals should incorporate brain injury survivors' lived experiences to understand the extent of the impact of brain injury fully. She expounded as follows:

Because brain injury is so prevalent, we tend to have more education for more people. When we looked at a non-traditional stroke, or a blow to the head, or someone's unconscious, or repeated brain injury--- you can actually look at what the actual outcome is. Some stuff is very classic, but people have no idea. It is really difficult to explain it to people who know better than you because they are medical professionals.

In addition, one participant has shared the misconceptions about brain injury that lead to perceived stigma. Adam, who has been struggling to get approved for disability benefits, shared, “They call me lazy; they call me unmotivated. They tell me to find a place, get to work, you know, they [service providers] have this attitude, in my opinion, that's sort of my take on it”.



Freese et al. (2016) suggest that community attitudes and stereotypes regarding ABI can lead to social stigmatization, increasing the daily life problems someone like Adam faces. As a young survivor whose life was upended by a brain aneurysm, Kaye suggests that patience and understanding, in general, would help someone with a brain injury reintegrate back into their community. She explained:

Some people need to be patient with brain injury, their understanding of brain injury. Because there are people who really don't. It gets very frustrating for some people like me. And I'd be like, why? By having more people aware of what brain injury is through education. Educating people for me is the way to go.

For close to two decades, Cor acknowledged that she should have been more proactive in advocating for herself when her injury happened. She shared:

There was nothing in the hospital. I am not sure now but at that time. There was nothing. Not to baby you but understand that there are some changes. To this day, I'm still scattered. You try to educate yourself; I do not think doctors are connected or collaborating.

### **Summary**

This chapter has presented a range of data that points to the role of power, knowledge, and language in disability related to the participants' access to care. In particular, the five interconnected themes, combined with the pre-interview survey's quantitative results, described the complexity and impact of the medicalization of brain injury to access to care.

Data highlighted the interaction of contextual and individual characteristics to access care. It is worth noting that the quantitative data drawn from survey questions were conducted during the pre-interview phase of data collection. Some of the survey items were fleshed out during the in-depth interview. They generated more expansive answers that contradicted the quantitative portion of the data.

The quantitative data findings showed that participants were least likely to experience refusal from service providers' treatment or services. However, more than half of the participants reported no access to a healthcare facility/specialist in their area. This finding was salient from those living outside Winnipeg, such as rural and northern Manitoba and those without insurance. Furthermore, survey data revealed that most participants experienced being allowed to ask questions to their service providers. Conversely, there was significant variation concerning the service provider's knowledge of brain injury. Participants from the homeless population most

likely experienced having service providers to understand their brain injury, while those who are retired and over 65 years of age were least likely to experience receiving service providers' help.

Transportation was also reported as a significant issue in accessing care, especially from participants living outside of Winnipeg, those who are no longer working or are retired, and those with Grade 10 or less education.

Many participants have issues with the qualification process in accessing services, waiting for services that they need, and experiencing stress and frustration in finding services. The majority of participants reported financial issues as a barrier to accessing services.

The quantitative data has shown that more than half of the participants agreed that transportation (51%) is a barrier to accessing services. In contrast, most participants perceived eligibility requirements and waiting periods for services affecting their access to care. Consequently, most participants are also stressed and were frustrated in finding services, not knowing where to find help, and not having the financial resources to access services.

The qualitative data identified the following five themes based on the conceptual framework described in Chapter 2: (1) contextual characteristics, (2) individual characteristics, (3) perceived need, (4) power and knowledge nexus, and (5) language.

The first theme, contextual characteristics, has six subthemes: working through the maze, uncoordinated system of care, transportation issues, geographic location, funding system, and mired in eligibility morass. Findings from this theme revealed that most participants found access to care like working through a maze, complicated by the long-term cognitive and behavioural consequences resulting from persistent symptoms of brain injury. Participants reported that the context of the health and social care system and organizational structures contributed to accessing services, especially with a lack of coordination in the system of care. There was a consensus on how the services are operating in silos. Doctors and specialists were often not working in tandem. There is a breadth of literature supporting a multidisciplinary approach to care for brain injury services. However, participants reported limited to non-existent services available in the community. Notably, outside Winnipeg, especially the Northern Manitoba residents are disadvantaged by their geographical location and transportation issues. While Winnipeg participants benefit from being closer to specialized services, transportation was still regarded as a factor affecting access to care when most participants had no driver's licence or access to a car. Alternatively, the variability and inconsistencies in services contribute to a long

waiting period for access to services. Participants who have resources from their income and/or a third party could pay for faster access for service fees.

In contrast, those with no financial resources have to wait on long waiting list to access specialized services such as physiotherapy, occupational therapy and neuropsychological assessment. Consequently, access to services is mired in an eligibility morass, making the application process daunting for the participants. This could be attributed to the lack of a standardized definition of functional ability across providers (Shared Health, 2019, p.166) and the weight placed on medical evidence.

The second theme, titled individual characteristics, has three subthemes, namely (1) gender, (2) race, and (3) socio-economic status. While the findings show no gender differences in access to care among participants, female participants raised gendered expectations from their interaction with service providers. Conversely, the race was not perceived to be a factor to access to care. However, participants who identify as Indigenous and persons of colour felt that they were treated like everyone else, which points to a colour-blind approach to care access. As a country with a diverse population, uniformity of access does not imply equitable access. Access to care should be offered to cater to the diversity of ethnicity and races, such as delivering culturally sensitive services.

Interestingly, findings reveal perceived privilege among participants who identify as white, whose view expresses that social services programs are made more available among Indigenous and people of colour. The majority of the participants were unemployed and receiving disability benefits or social assistance. As indicated in theme 1, the funding system affects access to care. Without good income and employment-related health benefits, most participants are hard-pressed to access fee-for care.

The third theme is the perceived need, which refers to the participant's reported symptoms and illnesses. Within this theme, the subtheme unmet needs were commonly experienced by the participants. Findings show that the complexity of the injury and not severity drives the need for services. Participants highlighted the prevalence of unmet cognitive, psychological and social needs. Further, it was also reported that the majority of the participants have limited access to specialized services relating to cognitive functions and psychological symptoms co-occurring with brain injury.

Moreover, findings from the power and knowledge nexus theme demonstrated the role of power distribution and knowledge production in obtaining access to services. In the subtheme arbiter of knowledge, participants solidified medical professionals' role as gatekeepers to specialist services. Additionally, biomedical evidence and the dominant expert knowledge are privileged over the participants' knowledge and lived experiences. There is support in the literature surrounding the lack of brain injury-specific knowledge among GPs. However, participants reported that their knowledge of their condition was frequently discounted in favour of the medical report. Ultimately, this leaves the participants powerless as the power rests on the experts' dominant knowledge and biomedical evidence.

Finally, the last theme is the language, which refers to the discourses surrounding disability. This theme also includes the subtheme (1) diagnosis and (2) disability vs invisible disability. The findings identified that discourses on diagnosis and, consequently, on disability rest on the medical model, affecting access to care. Several participants reported experiencing delayed diagnosis and misdiagnosis due to a lack of visible and physical evidence of their injury. The interview data also revealed the disability vs invisible disability discourse whereby participants construct discourses according to "survivor" discourse and "invisible disability" discourse. The survivor discourse is a way for participants to regain control of power over their own experience's narrative. Despite the complexity of their disability, participants were grateful they survived their injury.

On the other hand, the invisibility discourse is associated with perceived stigmatization, which creates disempowerment. The invisible nature of brain injury tends to be overlooked by service providers and affects individuals' access to care. The unique combination of cognitive, behavioural, and psychosocial consequences of brain injury adds to the complexity of diagnosis, treatment, and rehabilitation. Self-advocacy was one way that participants educate their family, the general public, and the service providers who were willing to listen.

## **Chapter Five – Discussion**

This chapter will be presented in three sections. First, I will present the study's findings and draw connections between the results, the literature review, and the conceptual framework developed for this thesis and as described in Chapter 2. I will then explore the limitations of this research, and lastly, I will make recommendations for social work education and implications for theory, policy and practice.

This thesis is the exploration of the lived experiences of ABI survivors in Manitoba in accessing care. Using a critical disability lens, specifically the Foucauldian perspective, I will examine the main findings grounded in this study's theoretical underpinnings. The framework provided by Andersen's behavioural model of care (2008) was used to determine how ABI survivors experience access to care. Consistent with the literature, the findings show that factors in the individual and the contextual domains interacted in the process of ABI survivors accessing care. While the role played by these factors was evident in the data, one key aspect that was revealed is the role of the power and knowledge and the interconnection to the individual's ability and capacity to access care.

### **Contextual characteristics and Access to Care**

With the medical focus on health, the social dimensions impacted by a brain injury are not often part of the conversation. The lived experiences of the participants are not separate from the systemic and structural issues. The findings highlighted the need for a coordinated response to specialist services, ABI-trained service providers, and interdisciplinary and multidisciplinary care. Furthermore, interview data suggests that these factors, as mentioned earlier, are affected by the limited availability of brain injury services. The participants' lack of services is understood as a lack of awareness and education on the long-term impact of brain injury on the participants' lives. Participants perceived that many service providers' lack of knowledge makes for muddy water to navigate in accessing care.

In the Manitoba context, findings reveal that healthcare services were coordinated in the confines of the hospital and in-patient care facilities. While this experience was positive for two (2) of the fifteen (15) participants, most of the participants in this study did not stay in the hospital long enough to access specialized services. The rest were either discharged to their homes or had never been admitted to the hospital. The findings were consistent with the

literature that I reviewed in Chapter 2 that highlighted that most emergency department populations were discharged without follow-up recommendations (Baptiste et al., 2005).

Findings of the current study revealed that irrespective of the severity of the injury or whether participants were admitted to the hospital or not, most claimed that they needed services for their ongoing symptoms related to cognitive and psychosocial issues. Although there was general satisfaction with the care that participants received while they were in the hospital and care facilities, they also revealed their dissatisfaction with the limited community-based services. In the study conducted by Lefevbre et al. (2015), ABI survivors in Quebec reported satisfaction on treatments received while in hospital but shared the same sentiments as the participants of this study regarding limited access and availability of post-acute care and services

Narrow eligibility requirements often bound the limited availability of community-based services. For instance, some literature suggests the need for psychosocial and disability services post-injury (Hodgkinson, 2000; Schatz et al., 2001). Hodgkinson's (2000) study believes that psychosocial disability following brain injury is a better predictor of service use than physical and cognitive disability alone. These findings are for the need for psychological and disability services supported by Schatz et al. (2001). In this study, findings revealed that these needed services were not readily available through Manitoba's provincial health insurance. One specific example is the unavailability of access to psychological services such as neuropsychological assessments. Neuropsychological tests are often used to estimate eventual outcomes or the degree of recovery expected following ABI (Schatz et al., 2001). Participants who had insurance were the only ones who could access the tests. More often than not, these tests were used to gauge eligibility for their benefits claims.

Findings from the current study also revealed that access to medical and rehabilitation services was limited to hospital and in-patient care facilities. Consistent with the study by Ta'eed et al. (2011), survivors with mild TBI sought psychology and cognitive services more often than those who had access to in-patient rehabilitation.

Limited service provision and lack of follow-up are not the only reasons for an uncoordinated care system. The results of this study indicated that service providers have insufficient knowledge of brain injury while working in a system that lacked the infrastructure to connect ABI survivors to available service providers. This is consistent with the literature. Solovieva and Walls (2014) cited a lack of knowledge among service providers as one of the

barriers to access to care. Similarly, De Jong and Frieden (2002, p.5) found that “inadequate provider knowledge or lack of 'disability literacy' or 'disability competence' in care settings leads to an inappropriate focus on ABI survivors' disabilities rather than on their presenting health problem”. The study adds to the growing body of research findings that suggests that healthcare providers' poor communication and lack of knowledge may affect a specific disability group such as brain injury survivors interacting with the healthcare system. A report from the NHCC/PHAC (2014) suggests that the complexity of neurological conditions such as brain injury requires a more coordinated service delivery. The lack of coordination of services was amplified by a participant with brain injury originating from a tumour. They experienced a seamless service delivery through Cancer Care Manitoba but not so when accessing services for brain injury issues. This example shows that Manitoba's health care and social service delivery systems can be integrated but are not for most of those with brain injury. Findings from the current study show that coupled with cognitive deficits and disability, an uncoordinated service system compounds the already difficult road to navigate in accessing care. Similar to findings reported in the literature, brain injury survivors experienced a greater need for service coordination in the period immediately following the incident, which typically tapered off with time and rehabilitation (Elliott & Parente, 2014; Kennedy & Chessell, 2013).

Although the literature suggests that Canada fares better than the United States in terms of health and social services coverage (Lasser et al., 2006), insurance coverage is still essential in accessing care, especially for those services not offered outside the hospital and care facilities such as physiotherapy, occupational therapy, vision therapy, neuropsychological assessments, and psychotherapy. Interview data suggests a continual negotiation between the service users and the service providers is needed regarding the disability health and the welfare systems. Across all interviews, brain injury services are determined by the funding available, such as private funding through the worker's compensation and insurance and public funding through the provincial healthcare coverage.

The affordability of services and interventions is the primary factor in accessing care. The *Canada Health Act* ensures access to medically necessary procedures. While studies have shown that outpatient rehabilitation and follow-up are associated with better brain injury recovery outcomes, it seems access to these services is limited or non-existent. Brain injury specialized services such as physiotherapy, occupational therapy, psychotherapy, speech therapy,

rehabilitation counselling, and neuropsychological assessments are not covered by public funding outside of in-patient facilities. There are three pathways through which a brain injury survivor can access specialized services: (1) as an in-patient in rehabilitation, (2) private funding through insurance and compensation benefits, and (3) incurring out of pocket expenses. The majority of participants in this study did not qualify for options 1 and 2, but at the same time could not afford the cost of services provided on a fee for services basis. The loss of employment from a brain injury affects the brain injury survivor's finances and their ability to access services through employment-related insurance.

In Canada, disparities in access between urban and rural areas have been a problem for many years (Sibley & Weiner, 2011). The most significant degree of inequality between rural and urban residents was access to specialist services, often located in a bigger city. Manitoba is no different from any other province or territory. The findings revealed that rural participants' access to community-based services is limited to homecare services. Any specialist services are delivered through MBTelehealth, especially in northern Manitoba and on reserves. Although specialists are available through MBTelehealth, this is limited to pediatric patients and not to adult survivors who are the target of this study ("Pan Am Concussion Program," n.d.). Findings from the current study are consistent with what was found in the literature- that there is a lack of resources in the rural area, and significant travel is required to access services. For brain injury, the faster access to treatment and services, the less devastating the impact (ERABI, 2019). However, with Winnipeg as the only location for specialized services, residents outside of the WRHA, especially those in the Northern Regional Health Authority, have limited access to care. This could be attributed to what is known; healthcare specialists are more challenging to access given a geographical location outside of a large city like Winnipeg (Pachkowski et al., 2009).

Findings further revealed that rural participants are greatly affected by transportation in accessing care as they must travel to Winnipeg for services. However, transportation is also a problem for brain injury survivors within Winnipeg based on their driving capacity. In Northern regions in Manitoba, issues related to distance and transportation affect access to care. Some remote communities depend on air and rail travel and ice roads in the winter (Pachkowski et al., 2009). Simultaneously, while travelling to Winnipeg for specialized services is complicated by distance, it is also expensive and time-consuming (Pachkowski et al., 2009).



Subsequently, findings revealed that brain injury survivors struggled with qualifying for private insurance and public income support programs such as EIA and CPP-Disability. Participants who had applied for compensation through work-related or collision-related insurance must prove that they are legitimately disabled. This further reifies brain injury into measurable and visible, which puts an invisible impairment, such as brain injury, in an automatically disadvantaged position. In Foucault's terms, medicine's anatomical atlas "directs attention to certain structures, certain similarities, certain systems, and not others, in so doing forms a set of rules for reading the body and for making it intelligible" (Armstrong, 1983 p.2). Insurance and compensation benefits encompass direct physical injuries, but the interview data revealed that the system nonetheless privileges the injury's visible and measurable aspect. In other words, the individual and their experience of illness and disability are not necessarily treated or compensated through insurance/compensation plans. They are compensated or treated if assigned to a diagnostic code (Phillips, 2003). Eligibility for compensation, therefore, rests on the power of the medical doctors and healthcare providers. Health and social services focus on identifying impairments and reinforcing the notion of defects by using medical evidence to validate that such impairments exist. There is little attention given to the difficulties in living and adapting to an injured brain or a body that never was who that person was.

Based on the conceptual framework presented in Chapter 2, access to care for brain injury survivors is achieved by focusing on the contextual and individual characteristics involved (Andersen, 2008). Contextual characteristics refer to the circumstances of and the environment surrounding access to care. In this study, relevant contextual characteristics on access to care provide us with a view of how integrated and coordinated health and social care services are structured. Using Foucault's governmentality as a framework, health and social policies that govern transportation, funding, and eligibility requirements are specific "technologies of the self" produced to shape and regulate individuals' and groups' conduct. According to Foucault, "technologies of the self" are ways in which the behaviour of those involved are normalized, disciplined, and sanctioned. While Manitoba is the main steward of health and social services, suggesting a dominating, sovereign role in access to care, Foucault regards the state as a relational ensemble. Governmentality is not the government itself, but the set of practices and strategies, governmental projects and modes of calculation, that operate on something called a

state (Dean, 2009). In understanding how access to care is governed, we need to question how power operates among those involved- be it service providers or service users.

Within the current study, I found that brain injury was problematized and predominantly focused on impairment. Therefore, the concept of disability became defined according to the medical-based definition of disability. As defined by Foucault, discursive regularities refer to “order, correlations, positions, and functioning to the way an issue is spoken about consistently” (Webb, 2013, p.48). In this context, ABI is defined based on the operational definitions set by agencies such as insurance and social services based on medical experts' medical evidence. The more debilitating effects of brain injury, mostly invisible but perceived to be more impactful for the ABI survivors, were not recognized as this knowledge is not part of discursive regularities.

Thus, ABI survivors became subject to the normalization principle's disciplinary technique based on classifying them as disabled or not. The dividing practice is employed whether the survivor has fully "recovered" or has been given the title of permanently disabled and, therefore, more deserving of care access. According to Sullivan (2005), hospitals and institutions are essential to the practice of objectivizing individuals between sick or healthy or curable or incurable, normal or abnormal. Walschidst (2005) suggests that social policies, rehabilitation programs, and other therapeutic practices aim to return the clients to pre-injury. As brain injury survivors, they are subjecting themselves to the medical power as the experts in treating them and deciding on what they deserve in terms of services. “Normalization becomes one of the greatest instruments of power whereby degrees of normality indicate membership in a homogenous social body to distinguish subjects from each other” (Foucault as cited in Tremain, 2017, p.57).

The medical model's influence over the definition of disability can be argued as one reason that survivors have a hard time meeting eligibility criterion. Duncan (2010) posits that the clarity of the medical gaze of measuring and knowing the injured body better than the injured person cemented the system of signs, which codified bodily loss with monetary gains. For injuries such as brain injury that could present as an ambiguous condition, the sick role's legitimacy cannot be derived from physical injury alone. According to (Campbell 2005, p.119), the “inclusiveness of the neoliberal conception of ‘citizenship’ hinges upon governing disability according to an ethics of normalization and minimization”. The healthcare and service system facilitates the subjectification of brain injury survivors into permanently disabled subjects so they

can be rendered visible and calculable (Campbell, 2005). The current study revealed that the enduring hegemonic compulsion on permanent disability as physical and visible defines the health and social policies, creating service navigational barriers. A piece of evidence from this study points to the understanding of brain injury according to the degree of physical and measurable impairment. For instance, one participant's application for vocational rehabilitation services was denied due to the absence of physical manifestation of cognitive impairment.

### **Individual characteristics and Access to Care**

Policymakers across Canada have struggled to find the best way to offer quality access to care across all populations regardless of gender, race, and socioeconomic background. In this study, Andersen's model (2008) proposed that access to care can be understood by exploring how contextual factors interact with individual domain factors. In the current study, the individual factors intersect with contextual domains based on how power and knowledge operate across various organized policies and practices or what Foucault called regimes of practices (Foucault as cited in Tremain, 2005).

Across interview data, participants' narratives about accessing care were focused on utilizing services and dealing with multiple demands that affect their access to care. The lived experiences of accessing and using services in having one's perceived needs met differ in terms of the participants' gender, race, and socioeconomic status. As previously discussed, there is a general lack of services and limited resources available for brain injury survivors to access. Having less capacity to find services and cope with a lack of resources puts ABI survivors in an even more disadvantaged position, especially concerning socioeconomic status. For example, when needed services require an investment of time and money, those with financial resources to access discretionary funds through family and savings will quickly pay for the needed services. When faced with the need for care, participants in this study have to make a trade-off to manage coping with their persistent ongoing symptoms or find another alternative such as free yoga or taking Advil for chronic headaches.

Contrary to the findings reviewed in Chapter 2 (Drapeau, Lesage, & Boyer, 2005; Iron & Goel, 1998; Lesage et al., 2006), no gender differences were found in either health or mental health service utilization. Both men and women accessed health and social services when they are available. However, in this study, gendered stereotypes played a role in their experience of

accessing care. Participants reported how stereotypes about women were associated with the experience of receiving care. For example, in the current study, one doctor, in particular, decided for a female participant overriding her own reproductive decision. A more nuanced understanding indicates that the male doctor was exercising identity power. According to Nancy Fraser (1989), this occurs when a man makes unintended use of his identity as a man to influence a woman's actions. Fraser (1989) posits that identity power typically operates in conjunction with other forms of social power.

Gender also played a role in how a participant's disability was perceived. Female participants perceived a gendered expectation for them to give up their careers because of their disability. This finding is consistent with Haag et al. 's (2016) finding that the social construction of gender contributes to women's experiences living with ABI, which impacts their access to care.

Findings revealed some differences in the extent to which different groups included in the sample perceived race as a factor affecting access to services. Furthermore, the interview data revealed that survivors who identify as Indigenous or visible minority did not see race as a factor in access to care. Participants felt that they were treated equally because they receive the same services as everybody else regardless of their race. Nevertheless, often, discrimination in health care is indirect and systemic (Halwani, 2004). According to Ontario Human Rights Commission ([OHRC], 2004), indirect discrimination occurs when everybody, regardless of their culture, religions, or linguistic background, received precisely the same services. A colour-blind approach does not result in equal access (OHRC, 2004). One can argue that service providers are not aware of the availability of culturally sensitive services. Findings from a participatory study conducted among Aboriginal clients in Ontario (Keightley et al., 2009) show the need for a specialized category for Indigenous clients recovering from ABI. Keightley et al. (2009) hypothesized that ethnic status might be correlated with ABI factors such as poverty, living in dangerous or unsafe conditions, and limited opportunities. These factors increase the individual's susceptibility to traumatic events, injuring their brain and one's likelihood of seeking treatments.

However, participants of the current study who belong to Indigenous and visible minority groups did not perceive their race as a factor for differential access. They saw it as more of a product of their location and socioeconomic status. For the Indigenous population living in Northern Manitoba and on a reserve, lack of access to services was seen as a result of location.

One interesting finding from this study was how people who belong to the Indigenous and visible minority groups did not feel that they were treated differently and did not see race as a factor in accessing their services, but this was not the case for those who identified as White. It could be argued that when differential treatment becomes normalized, recipients do not see it as having an impact on accessing services. Despite belonging to the same socioeconomic status, survivors who identify themselves as White assumed a perceived privilege of accessing care. However, they did describe being discriminated against because they identified as White and “does not belong there”. Wetts and Willer (2018) theorize that perceived macro-level trends in racial standing shape whites' welfare policy views. They argue that whites perceive threats to their relative advantage in the racial status hierarchy when they perceive programs (i.e. welfare services) primarily benefit minorities.

Most participants' financial struggles were because they could not resume prior employment and are receiving disability benefits. Some participants have families with other income sources. However, those who live alone or are the sole providers have to adjust to the lower-income and resulting financial status. According to Statistics Canada (2015), out-of-pocket health care expenditures have increased for Canadian households, particularly those in lower-income quintiles. Specialized services, prescriptions outside the hospital and physician care are becoming less equal across different income levels. Recent data from Statistics Canada (Wall, 2017) found that persons with disabilities account for 41% of the low-income population. All else being equal, persons with a mental-cognitive disability, such as a brain injury, had over 20% probability of belonging to the low-income group compared to 14% of people with a physical-sensory disability (Wall, 2017). As a result of economic exclusion, most ABI survivors have a reduced capacity to use health care services that are not covered under provincial care. Further, the study also revealed that there was no offering of culturally sensitive services to the survivors. For example, aboriginal services were not offered to survivors who identify themselves as indigenous peoples.

In the current study, participants' reports varied ways that they have accepted their post-injury experiences. When they were ready to accept their need for support and services, it was challenging for many. ABI survivors possess poor knowledge of what is available, and the need for guidance in navigating the health and social service systems was magnified. Findings reveal

that the lack of integration of community-based supports with the medical treatment in the continuum of care affects the ABI survivor's access to care.

The high prevalence of unmet emotional, cognitive, and social needs is consistent with other studies documenting severe behavioural problems that can persist even when physical impairment is minimal (Heinemann et al., 2002). In the absence of formal support services in the community, participants appeared to have developed coping strategies to deal with the consequences of brain injury. Although there was a formal support service available through the local brain injury association, this study's participants were unaware of these services. I excluded ABI survivors known to the local brain injury association I work for ethical reasons. Most of the services that participants required are services that will help them achieve independent lives post-injury, such as cognitive and neuropsychological services, coordinated supports to help with transportation, mental health support, and daily life skills. All of this could be addressed inexpensively by employing support workers. However, due to the injury's invisible nature, there is great difficulty meeting the eligibility criteria to access the available community-based services.

Health professionals and service providers often play a central role in making decisions for persons with an ABI. These decisions need to be responsive to the needs of the ABI population. Thorough knowledge of ABI and its medical and psychosocial consequences is needed when making these decisions. Although the medical model illuminated the long-term consequences of brain injury, including the physical, cognitive, and behavioural effects, it also cemented medical experts' role in determining brain injury survivors' needs. The broader social effects of brain injury and functional changes due to cognitive and executive difficulties are not well supported by the absence of mental health and social supports. Kreutzer et al. (2002) suggested a more holistic health approach with ABI is necessary to avoid the person's treatment solely based on symptoms.

This study revealed that those who hold power within service navigation reinforced the dominant impairment discourses on brain injury, resulting in the survivors' unmet needs. However, individual differences, challenges, and perceived needs that were not captured within the boundaries of the medical evidence were perceived by participants as not acknowledged and, therefore, not requiring services for them. The impairment discourse and medicalization of brain injury limit what can be quantified as impairment, what survivors' post-injury abilities

are, and what kind of supportive services they receive. This can be analyzed using Foucault's theory of medical gaze, in which a person and her or his condition are separated. The gaze, defined as the “act of seeing”, is central to how the body is assessed within the context of normality (Sherry, 2006, p. 48). It is a form of social control whereby the body separated from the person can be analyzed, probed, and examined (Foucault as cited in Blackhawk, 2016). Foucault traced the history of medical knowledge through the medical gaze, which legitimizes medicine's power to make a disease/impairment knowable (Hughes, 2005). This medical gaze is how service providers exert power through their role as purveyors of services.

Based on the conceptual model, access to care is the marriage of contextual and individual characteristics. Theme 1 discussed the importance of contextual factors in shaping the services available for ABI survivors. Conversely, survivors must manage the contextual factors, such as waiting lists, transportation, ability to pay, and eligibility criteria. Within the current study, it was found that meeting the requirements shaped by these macro forces is much more difficult when individuals have inadequate sources of income and lower socioeconomic status. From a Foucauldian perspective, this demonstrates how the micro, meso and macro levels of health and social services are shaped by power dynamics (van Rensburg, Rau, Fourie & Bracke, 2016). The contextual factors such as norms and structures become established and institutionalized through relations of power. These norms and structures reconstruct the identities of individuals and social actors. In these cycles of construction and reconstruction, people and groups (subjects) become positioned in specific ways related to dominant norms and structures (van Rensburg et al., 2016).

### **Power/Knowledge Nexus and Access to Care**

It was apparent from participants' accounts that the lack of access to services is often caused by a lack of referral and proper diagnosis by professionals who are the gatekeepers to these same services. One can argue that a brain injury's invisible nature contributes to the lack of understanding of its many facets as a chronic condition. This is particularly important because medical practitioners have been given the inherent power to decide how survivors can and will access care. These practitioners have gained their expertise from reading textbooks and being deemed experts in their field. They are in a position to enforce their knowledge. Participants in this study have lost their ability. They were not allowed to use their knowledge of their situation.

Medical power prevails (Sullivan, 2017). Despite survivors clamouring for the truth about their condition, there is a general lack of knowledge or unwillingness to share on service providers. This causes frustrations for many survivors. Their frustration is significantly heightened regarding the lack of information on ABI recovery's long-term consequences and trajectory. Participants surmised that medical professionals did not know the answers, especially when some information received is inconsistent and contradictory.

Using Foucault's medicalization concept, physicians and service providers have the inherent power as they are viewed as having expertise. Participants perceived that their personal accounts of their symptoms are often denied and dismantled with other co-occurring medical disorders. For instance, post-injury, survivors often experience depression, anxiety, or impulse control. Yet these common consequences were regarded as a mental disorder such as adult onset conduct disorder.

Fricker (2007) explains these power relations as a form of testimonial injustice. In the current study, credibility excesses are assigned to service providers while ABI survivors are assigned credibility deficits because service providers are viewed as experts on the subject. Brain injury survivors looked to their general practitioners for answers to their medical questions when the answers would be best-given specialists who would have more training in particular areas. Participants perceived the doctor as being able to provide the information they need, thus attributing an excess of credibility to the doctor.

There appears to be a credibility deficit assigned to brain injury survivors, as seen when their general practitioners dismiss their knowledge about their condition. According to Fricker (2007), this is a case of testimonial injustice, distinct from epistemic injustice. It is a kind of injustice in which someone is wrong, specifically in her capacity as a knower. Findings in this current study revealed that participants were denied brain injury diagnosis based on their self-reported symptoms. ABI survivors' self-reports were not seen as a legitimate medical cause in the absence of medical evidence.

On the other hand, the general practitioner and other service providers are esteemed in their capacity as knowers. The primary characterization of testimonial injustice is a matter of credibility deficit and not credibility excess. In other words, testimonial injustice occurs when a brain injury survivor sees their practitioner and is not listened to and believed about their symptoms. Therefore, they are not afforded credibility, which results in a credibility deficit and,



consequently, a testimonial injustice (Fricker, 2007). Healthcare professionals and medical doctors possess epistemic privilege owing to their training. However, ABI survivors also have an epistemic privilege that deserves to be recognized and respected.

While testimonial injustice pertains to individuals, hermeneutical injustice happens when resources are absent or impoverished and not easily accessible (Fricker, 2007). Findings from this study show that the lack of knowledge on the long-term consequences of brain injury among general practitioners affected the participants' referral to specialists and specialized services, which affects their access to care. ABI is a complex condition, with a broad array of sequelae. Participants reported delayed diagnosis and misdiagnosis, which could indicate an instance of hermeneutic injustice by healthcare professionals who were supposed to be knowledgeable in training and practice.

Fricker (2007) argues that the most severe forms of testimonial injustice are both persistent and systematic. In all such injustices, the subject is wrong in their capacity as a knower. The capacity to give knowledge to others is one side of that often-cited capacity so significant in human beings, namely the capacity for reason. There was a general feeling of frustration from the participants when they voiced their attempts to obtain a diagnosis. Their capacity as a giver of knowledge was often dismissed and ignored. In the context of oppression, the powerful will be sure to undermine the powerless in just that capacity, for it provides a direct route to undermining them in their very humanity (Fricker, 2007).

In general, epistemic injustice happens to ABI survivors based on the continual use of a biomedical framework as a basis for diagnosis. The significant weight placed on the medical evidence reinforces the dominant discourses on the medicalization of brain injury as a disability.

### **Language and access to care**

The combined effects of medicalization and the dominant discourses on brain injury shape the language used to describe a permanent disability, specifically a permanent brain injury. However, Langlois, Rutland-Brown, and Wald (2006) found a strong tendency among professionals to overlook ABI's invisible symptoms required for proper diagnosis. Foucault used the metaphor "carceral archipelago" to describe the medicalized subjectivity from exercising power and expertise (Foucault as cited by Blackhawk, 2016). Using the medical gaze, the hidden truth of the body is never invisible but always immediately visible. For brain injury survivors

seeking a diagnosis, the often-invisible nature of their impairment leaves their account of symptoms as not legitimate in the absence of visible medical evidence. The lack of a diagnosis often thwarts the often-necessary long-term support and ongoing rehabilitation to deal with their impairments. Those without an impairment for which a precise diagnosis exists will bear the brunt of the inadequacies of access to services (Sherry, 2006). Participants in this study reported that having a diagnosis legitimates public and insurance/compensation funding needed to access services. While diagnosing a condition that often manifests in a unique combination of symptoms is challenging, participants expressed a need to validate their condition as legitimate and not just “all in their head”.

Foucault's medical gaze concept helps explain how survivors identify with their new way of being and why they behave accordingly. “The gaze, defined as the ‘act of seeing’, is central to how the body is assessed within the context of normality” (Sherry, 2006, p. 48). It is a form of social control whereby the body separated from the person can be analyzed, probed, and examined (Foucault as cited in Blackhawk, 2016). Foucault traced the history of medical knowledge through the medical gaze, which legitimizes medicine's power to make a disease/impairment knowable (Hughes, 2017). This establishes the distinction between normal and pathological, which sets the dualistic logic that invalidates the ABI survivor on the grounds of bodily difference from a medically fabricated norm (Hughes, 2017).

Furthermore, Hughes (2017, p. 83) added that “this regime of truth made it possible to ‘see’ impairment and to ‘say’ disability as a physical or mental deficit”. As Foucault reiterates, “the invention of the medical gaze brought about a shift in understanding, what was once concealed became revealed through the illuminating power of the gaze, and in so doing, the medical knowledge was considered free from distortion as it brought unprejudiced truth to light” (Foucault as cited in Blackhawk, 2016, p.3). One can argue that cognitive impairments such as brain injury, which are not physically visible outside of this realm, are not considered a disability.

The impairments associated with brain injury highlight the changes from the pre-injury body but do not consider the lived experience of having an impairment that society regards as outside of the “normal”. According to Tremain (2017), impairment is an element of the apparatus of disability. Foucault's biopower concept is central in understanding impairment that, like disability, is the product of power relations (Foucault as cited in Tremain, 2017). Biopower is

seen as a political tool to problematize disability (Tremain 2017). The medical understanding of brain injury is that it is just an impairment that needs fixing. ABI survivors are required to provide medical evidence to legitimize their disability. Foucault (1973) posits that biopower enacts power by reproducing dominant discourses, such as disability, as a problem. In the current study, service providers have come to work under the biopower regime by treating and responding to the "problem" of disability. In the context of this thesis, brain injury as a disability represented a medical defect that biopower has to manage, regulate and govern through medical reports, assessments, and treatment from medical professionals.

Similarly, participants identify more with their impairment than as a person with a disability. Participants were often told that nothing could be done with their current condition. Yet, they continue to experience difficulties and deficits. Some participants were seeking neuropsychological assessments (Dawn, Trace, Natalie), medical reports concerning their CT scans (Cor, Bailey), and further treatments (Adam) in order to identify the impairment to be "fixed". However, it is interesting to note that there is an inherent power struggle for brain injury survivors to divulge and consequently embrace their newfound identity as someone living with a brain injury. There is ambivalence on how individuals embody their brain injury. Stark differences in acceptance emerge between those who are more educated and employed than those who have relinquished the idea of working again. While those who are employed recognize their deficits, they often do not embrace the idea that they have a disability. Participants who were able to resume employment reported that they did not think of themselves as disabled because they were denied disability benefits (CPP and Long-term Disability) and were able to work.

Participants' ability to manage the impact of brain injury on their lives is one of the most challenging aspects of seeking health and social services. According to Cohen-Mansfield et al. (2006), identity change can have problematic implications when dealing with traumatic life events or health-related diagnoses. Impairments, as a result of a brain injury, have many social dimensions and unintended consequences. One unintended consequence of a brain injury that emerged from this study is homelessness. A significant number of participants belong to the homeless population. Thus, this study supports the extant literature that brain injury prevalence is high among homeless individuals. A history of brain injury is associated with poorer health and general functioning (Stubbs et al., 2020). Although many factors contribute to homelessness, for

the brain injury participants in this study, access to services could decrease ABI's representation in this population.

### **Conclusion**

This study has provided new and different understandings of access to care from ABI survivors' lived experiences. It has illustrated the many facets of service delivery and the wide-ranging and complex consequences of living with an injury that is often treated as invisible. Compared to the general population, ABI survivors are more likely to experience health issues and challenges in navigating the healthcare and social services systems. Within the literature reviewed in this study, researchers have commonly attributed the barriers and facilitators of healthcare and social service access from administrative data analysis or examined the effects of service access on health outcomes. There was scarce literature that explored the understanding of access to service from lived experiences. In particular, there was no single study in Manitoba that examined how ABI survivors' access and manage services related to their condition.

This qualitative study aimed to explore and examine ABI survivors' lived experiences in accessing care in Manitoba. In this study, I employed a Foucauldian perspective to bring together the framework from Andersen's Behavioural Model (2008) and critical disability theory to examine the role of power/knowledge and language in how ABI survivors utilize services. Using Foucault's theories of governmentality, biopower, medical gaze, and normalization, I understood how ABI survivors perceived their disability, how the dominant discourses of ABI influenced the knowledge that is privileged, and how power was exercised within service navigation and between the interactions with service users and service providers.

This study highlighted that ABI's medicalization contributed to shaping the available services for survivors. The hegemonic discourses informed by the medical model influenced the knowledge construction on what it means to have a brain injury. Participants' experiences of their brain injury that fall outside the medical experts' knowledge realm were not seen as legitimate. As a result, this dominant knowledge construction affects diagnosis and referral, and consequently, access to services. Using a critical disability lens, brain injury issues were examined as a health concern related to social, political, and systemic structures. Disability is a social experience; thus, it can be affected by social variables such as gender, age, socioeconomic status, and ethnicity (Sherry, 2006). Based on the findings, ABI is often labelled as an

impairment supported by medical diagnosis. Despite the progress made in advancing the social model of disability, the current starting point for disability services still rests on the impairment discourses. Survivors perceived a negative stigma that comes with the diagnosis of a brain injury. However, at the same time, it also legitimizes their condition that is often unseen. The impairment discourse informed the understanding that it facilitates service providers and medical professionals as hegemonic decision-makers to diagnose and refer ABI survivors to services. Outside of this hegemony, ABI survivors are deemed ineligible to access services.

Based on the literature review, the characteristics of organizational and systemic structures, such as lack of coordination and inconsistent referral systems, have been identified as barriers to service delivery that affect meeting the survivors' perceived needs for services. It was found in this study that ABI survivors' perceived unmet needs were based on the differing knowledge construction between the service providers and service users. For instance, an ABI survivor's understanding, expectations, and ideas for "recovery" often conflict with what the medical community often espouses. For example, participants discharged from the hospital often lost or experienced diminished contact with their specialists after the first two years of medical recovery. Other participants have been told that nothing can be done with their injury but to live with it. These differences contributed to service navigation barriers and how ABI is problematized in the service system. The power-knowledge nexus is reflected in an ongoing negotiation between the experts (service providers) and the survivors. In the absence of a diagnosis and medical evidence, ABI survivors' knowledge of their condition, such as self-reported symptoms, was not considered in making a diagnosis. Consequently, when the voices of those with lived experiences are silenced, it denies them the testimonial justice to reconstruct discourses on their condition.

Last, this study placed power/knowledge and language as front and centre in understanding access to care. ABI survivors often face difficulties in meeting eligibility criteria owing to the invisible nature of the disability. This study's unmet needs include access to community-based specialized services, quicker access to specialists and resources, service navigation support, and mental health services. For the contextual characteristics such as health and social policies, transportation, the funding system and geographic location, resources and services should be designed so that survivors, regardless of their race, gender, socioeconomic status, and perceived need, can reasonably access the services.

### **Limitations of the Study**

There are several limitations when using and interpreting this study. First and foremost, most of the participants were from Winnipeg, the province's largest urban area. The rural area of Manitoba represents 44% of the population and is highly dispersed. Beyond this, most participants were highly functional and may not have the needs of those with severe outcomes. The interview was also conducted in English only. It may have limited data on the effect of language barriers on access to care. Finally, given the small sample, direct generalizability to the broader population should be made with caution.

### **Implications**

#### **Implications for social work education**

Access to care has been studied in various settings, but most of the research is based on a positivist methodology. The current research utilized the popular model of healthcare behaviour by Andersen (2008) and incorporated critical disability theory aspects.

It has also been illustrated that within social services, the hegemonic impairment lens of disability has been identified as affecting all aspects of care access. Participants in this study described how current discourses on disability shaped health and social policies and how the social actors involved responded to brain injury survivors deserving of services.

Participants also perceived that service providers lack the knowledge and awareness to effectively address brain injury survivors' needs. Thus, it is necessary to redefine the current knowledge that is privileged, and that wields power over access to care. Academics can educate social work students to develop the capacity to critically analyze how the dominant discourses have disadvantaged brain injury survivors whose disabilities are often seen as invisible. As social work is focused on social justice, educators have the moral obligation to dispel the impact of the dominant discourse on disability and incorporate the voices of ABI survivors' lived experiences. Despite advances and the popularity of the social model of disability, health and social policies and eligibility requirements for disability benefits are still located in the biomedical realm. Social work education needs to teach students to critically view disability in the same way that gender and race have been given the critical eye. Like any invisible disability, brain injury as a condition is often misunderstood, leaving the individual excluded from full citizenship and participation in society. Social workers are part of the multidisciplinary team of experts who deal with brain

injury patients in the acute and post-acute phases of recovery. Therefore, increasing understanding of the myriad and broad consequences of brain injury will positively impact the survivor's post-injury independence and quality of life.

### **Implications for social work practice**

Participants in the current study described a lack of interaction and contact with social work. In this study, survivors reported limited interaction with a social worker. When it happened, the social worker was in the role of purveyor of disability and welfare benefits. Social work can and can do much more for people with disabilities, from early intervention in the acute phase to the reintegration of the ABI survivor into the community.

Social workers whose ethical obligation is to further social justice can do much for those excluded. Social workers have the power to reconstruct the existing dominant discourses of what knowledge is being privileged. Social workers can challenge the hegemony of medical expertise by integrating awareness of the challenges brain injury survivors live. Social workers can also critically reflect their understanding of disability, specifically brain injury, in social work practice. They can engage the agency/hospital to listen to ABI survivors and understand the barriers to access to care that they experience. The current study's findings highlight the opportunity to build social work's capacity to advocate for clients with brain injury and use their discretionary power to improve brain injury survivors' lives.

### **Implications for policy**

The dominant medical discourses inform health and social policies that govern access to care. As eligibility criteria are concerned, the recognition of knowledge and truth rests with the "experts". Participants expressed that their needs were not met because of ineligibility for services. An assessment of healthcare and social services program policies should be made to locate the gaps in coverage along the continuum of care for ABI survivors, which prevents them from receiving immediately needed services.

In this study, the need for care was not confined to the hospital's four walls but rather in the community and the micro-level transactions between service providers and service users. Access to care should be based on social equality principles—which means that "patient-centred" care should include ABI survivors' knowledge and voice in the construction of the dominant discourses. According to Foucault (1973), power is productive. An intervention plan

based on shared knowledge construction reduces the power differential between the service provider and the service user.

These arguments can be used to advance policy changes concerning accessing care. Policymakers should redefine the focus of disability from impairment to the disabling barriers that prevent the individual from achieving independence and quality of life. Furthermore, policy formulation and analysis should be informed by the ABI survivors' lived experiences and the impact that the injury has on their lives, their families, and their futures. There should also be flexibility in policies to reduce health outcome disparities by incorporating individual factors.

Lastly, service navigation has been identified as operating in silos and isolation. It is time for intersectoral collaboration and jurisdictional unity to improve access to and the efficiency of distributing fiscal and service resources for all, especially those disadvantaged because of their geographic location, gender, socioeconomic status and/or race. Policy developers should examine integrating services for brain injury survivors by looking at other chronic diseases and illnesses service delivery frameworks like CancerCare Manitoba<sup>10</sup>.

### **Implications for theory**

Andersen's behavioural model of care has been applied to many populations, including vulnerable populations (Gellberg & Andersen, 2010). The model was beneficial as a guiding framework to organize the factors crucial to accessing care. The model was also used to answer the research question on the interaction between the contextual and individual domains.

Furthermore, consistent with Andersen's model (2008), the individual's health need was a driving factor for access to services. However, data from this study shows that evaluated need is often affected by the power and knowledge nexus, which leaves ABI survivors without proper diagnoses, which, in turn, eventually impacts their access to care. In healthcare and social service systems, power/knowledge can be exerted in the context of legitimizing the language of biomedicine under service providers' training and expertise. In modern healthcare, there is a burgeoning trend of patient-centeredness in service delivery. However, participants in this study revealed that shared power was not exercised in their access to care. This study's significance to access to care stems from incorporating a critical disability lens and its role when examining

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<sup>10</sup> CancerCare CancerCare Manitoba (CCMB) is the provincially mandated cancer agency and is responsible for setting strategic priorities and long-term planning for cancer and blood disorders.



relationships by utilizing concepts of power distribution, knowledge construction, and discourses. I would argue that a critical disability lens merits a place in improving access to care for those living with a disability. The argument for a redistribution of power and reconstruction of knowledge for care is pivotal to dismantling the existing hegemony that affects ABI survivors' lived experiences.

### **Recommendations for Future Research**

My interest in conducting this research stems from the desire to explore the many aspects of accessing care for brain injury survivors and identify ways to address the inequity. Within the current literature, there is a limited qualitative research conducted on ABI survivors' lived experiences. This study's findings could provide ideas to improve service delivery and possible policy change to improve ABI survivors' lives. As an indirect result of the recruitment strategy, this study's data has revealed a significant sample from the homeless population. Expanding the settings for data collection to include this population subset is a good starting point for further expanding this research. Findings from this study raised questions on homelessness's role in the risk of acquiring a brain injury.

Similarly, during recruitment, there were a significant number of inquiries from caregivers and family members who wanted to share their experiences when trying to access care for their injured loved ones with severe cognitive deficits. It would be beneficial to conduct a study among those whose lives centred around navigating services and resources for ABI survivors who were dependent on their care. While differences in accessing care were found based on geographic location, further study should aim for more sampling from ABI survivors outside Winnipeg.

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## **Appendix A**

### **Determination of Decisional Capacity**

Prior to seeking consent, the researcher will actively engage the participant in the informed consent process to gauge functional capacity to understand the study.

1. Review the information letter, study details and consent form during the pre-interview session.
2. Encourage and answer all questions and re-explain any information that is not clear.
3. Participants will be asked the following questions:
  - 3.1. What is the purpose of the study that was just described to you?
  - 3.2. What makes you want to consider participating in this study?
  - 3.3. Do you have to be in this study if you do not want to participate?
  - 3.4. If you withdraw from this study, will you still be able to receive services from social and health care services?
  - 3.5. If you participate in this study, what are some of the things that you will be asked to do?
  - 3.6. Please describe some of the risks or discomforts that people may experience if they participate in this study?
  - 3.7. Please describe some of the benefits of this study.

Note: incorrect responses will serve as a cue to re-explain and reassess

## Appendix B

### ORGANIZATION/AGENCY RECRUITMENT LETTER

Date \_\_\_\_\_

Dear \_\_\_\_\_,

My name is Gladys Tabal-Hrabi, and I am a Master of Social Work student from the University of Manitoba. This letter is a request for *[name of organization]*'s assistance with a project I am conducting as part of my degree requirements under the supervision of Dr. Sid Frankel. The title of my research project is **“Access to Care for Acquired Brain Injury Survivors: A Qualitative Inquiry.**

The purpose of this study is to provide an opportunity for brain injury survivors to express their experiences in accessing health and social services. Knowledge and information generated from this study may help service providers improve the quality of service provision, as well as helping us to understand the needs of the brain injury survivors as experts on their condition.

I hope to connect with brain injury survivors who are engaged in the programs of the [name of organization] to invite them to participate in this research project. The study involves a screening interview, which will be conducted over the phone, a pre-interview over the phone or in person, and an individual 45-90-minute interview at the participant's choice of time and location. In instances where an in-person interview is not possible, a telephone interview will be provided as an option. At the end of this study, I will share the knowledge developed with other researchers, service providers, government agencies, and health facilities.

To respect the privacy and rights of the *[name of organization]* and its participants, I will not be contacting the brain injury survivors directly. What I intend to do, is provide the *[name of organization]* with information flyers to be distributed by the [name of organization] at its discretion. Contact information will

be contained on the flyers. If a brain injury survivor is interested in participating, she or he will be invited to contact the researcher to discuss participation in this study in further detail.

Participation is entirely voluntary. All participants will be informed and reminded of their rights to participate or withdraw at any time in the study. Participants will receive a \$15 Tim Hortons or Real Canadian Superstore gift card for their time as an appreciation of their participation. Participants will receive an information letter, including detailed information about this study, as well as an informed consent form.

To support this study's findings, quotations and excerpts from the stories will be used and labelled with a non-identifying indicator to protect the identity of the participants. Names of participants will not appear in the thesis or reports resulting from this study. Participants will not be identifiable and only described by aggregating demographics in descriptive statistics.

If the *[name of organization]* wishes the identity of the organization to remain confidential, a pseudonym will be given to the organization. All data will be securely stored and destroyed at the completion of the study. Finally, only the research advisor, Research Ethics Committee and myself will have access to these materials.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Manitoba Psychology/Sociology Research Ethics Board. However, the final decision about participation belongs to the *[name of organization]* and the participants.

If you have any questions regarding this study or would like additional information to assist you in deciding on participation, please contact me at [REDACTED]

[REDACTED] or email me at [tabalg@myumanitoba.ca](mailto:tabalg@myumanitoba.ca). You may also contact my supervisor, Dr. Sid Frankel, at [sid.frankel@umanitoba.ca](mailto:sid.frankel@umanitoba.ca)

I hope that the results of my study will be beneficial to the [name of organization], to your membership, and the communities of brain injury survivors and families and caregivers, as well as the broader research community. I very much look forward to speaking with you and thank you in advance for your assistance with this project.

Yours sincerely,

Gladys Tabal-Hrabi

Master of Social Work (candidate)

Faculty of Graduate Studies

University of Manitoba

Dr. Sid Frankel

Faculty Advisor

Faculty of Social Work

University of Manitoba



**Appendix C**  
**SCREENING INTERVIEW**

I want to express my gratitude for your interest in participating in this study. I would like to ask you several generic questions. Do you agree to go over some questions with me about yourself and your injury?

1. How long ago were you first injured?

- ☐ 2-5 years
- ☐ 6-10 years
- ☐ over 10 years

2. How many brain injuries have you sustained?

- ☐ one
- ☐ two
- ☐ three
- ☐ more than three

3. Were you admitted to the hospital as a result of your most recent injury?

- ☐ Yes
- ☐ No

4. Have you been formally diagnosed with acquired brain injury?

- ☐ Yes
- ☐ No. Why not? \_\_\_\_\_

5. What was the cause of your acquired brain injury?

- ☐ Motor vehicular collision as driver/passenger
- ☐ Motor vehicular collision as pedestrian/cyclist

- ☐ Assault/Abuse
- ☐ Near drowning
- ☐ Falls
- ☐ Sports injury
- ☐ Lack of oxygen (anoxia)
- ☐ Firearms/Gunshot
- ☐ Suicide attempt
- ☐ Poisoning/ drug overdose
- ☐ Stroke/ Brain hemorrhage/Aneurysm
- ☐ Tumour/Tumour removal
- ☐ Viral illness such as meningitis/encephalitis
- ☐ Other: \_\_\_\_\_

6. In the past 12 months, have you accessed health and social services?

- ☐ If Yes. How Often? \_\_\_\_\_
- ☐ No

7. Are you over the age of 18?

- ☐ Yes
- ☐ No

8. What gender do you identify with?

- ☐ Male
- ☐ Female
- ☐ Other: \_\_\_\_\_

9. Where is your area of residence?

- ☐ Rural Manitoba
- ☐ Brandon City

- ☐ Winnipeg City
- ☐ Northern Manitoba (Swan Lake, Thompson, Churchill)

10. What is your current marital status?

- ☐ married
- ☐ living common-law
- ☐ widowed
- ☐ separated/divorced
- ☐ single, never married

11. What is your racial ethnicity? Note: You may report more than one group.

- ☐ White
- ☐ Indigenous peoples (First Nations, Metis, Inuit)
- ☐ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- ☐ Chinese
- ☐ Black
- ☐ Filipino
- ☐ Latin American
- ☐ Arab
- ☐ Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai, etc.)
- ☐ West Asian (e.g., Iranian, Afghan, etc.)
- ☐ Korean
- ☐ Japanese
- ☐ Other- specify

12. What is the highest level of education you completed?

- ☐ Grade \_\_\_\_
- ☐ Certificate or Diploma

☐ Undergraduate degree

☐ Graduate degree

☐ Other: \_\_\_\_\_

13. What is your current schooling status? Note: You may have more than one response. Please select all that apply.

☐ Part-time student

☐ Full-time student

☐ Work part-time

☐ Work full-time

☐ Retired

☐ Self-employed

☐ Not working

☐ Other: \_\_\_\_\_

14. To which of the following income brackets does your 2018 household gross income belong?

a. under \$25,000

b. over \$25,000 but below \$65,000

c. over \$65,000

15. Do you have benefit from private health insurance?

☐ Yes

☐ No

16. Are you receiving disability plans' benefits? If yes, which one?

☐ Canada Pension Plan- Disability

☐ Employment Insurance sickness benefit

☐ Employment and Income Assistance- Disability

☐ Private or employment related to disability insurance

- ☐ Manitoba Public Insurance
- ☐ Worker's Compensation board

You may opt to complete this interview through email. Your response is needed as soon as possible. Please send the completed questionnaire to the email address provided.

**Appendix D****SERVICE UTILIZATION PRE-INTERVIEW**

**Please indicate the services you have accessed in the past 12 months and how many times you have accessed them.**

**MEDICAL/REHABILITATIVE SERVICES**

- ☐ Primary care visits (Doctor's Office, Nurse Specialist). How many times?  
\_\_\_\_\_
- ☐ Neurologist/Neurosurgeon/Other specialist. How many times? \_\_\_\_\_
- ☐ Vision services that address the effects of brain injury. How many times?  
\_\_\_\_\_
- ☐ Addiction services. How many times? \_\_\_\_\_
- ☐ Mental Health Services. How many times? \_\_\_\_\_
- ☐ Alternative therapy (chiropractor, acupuncture, naturopathy). How many times?  
\_\_\_\_\_
- ☐ Physiotherapy. How many times? \_\_\_\_\_
- ☐ Occupational Therapy. How many times? \_\_\_\_\_
- ☐ Speech and Language Therapy. How many times? \_\_\_\_\_
- ☐ Nutritionist/Dietitian. How many times? \_\_\_\_\_
- ☐ Emergency Room. How many times? \_\_\_\_\_

**SOCIAL SERVICES**

- Case management.** How many times? \_\_\_\_\_
- Behavioural support services (relearn skills).** How many times? \_\_\_\_\_
- Assistive Technology services.** How many times? \_\_\_\_\_
- Medical equipment services.** How many times? \_\_\_\_\_
- Respite care/ Home care.** How many times? \_\_\_\_\_
- Social work services.** How many times? \_\_\_\_\_
- Counselling services/Therapy.** How many times? \_\_\_\_\_
- Transportation services.** How many times? \_\_\_\_\_

**Housing assistance.** How many times? \_\_\_\_\_

**Financial Management Assistance.** How many times?

**Vocational/ Employment Assistance** How many times?

Others: \_\_\_\_\_

In accessing health and social services, please tell me how often have you experienced the following:

|       |        |                     |                     |
|-------|--------|---------------------|---------------------|
| Never | Seldom | Some of<br>the time | Most of the<br>time |
|-------|--------|---------------------|---------------------|

1. Being refused treatment or services  
from providers

2. Health care facility/ specialist/  
service need is not available in your  
area

3. During appointments, you are  
allowed to ask questions to your  
service providers

4. Service providers (doctors,  
therapists, etc) explain and help you  
understand your brain injury

5. You have difficulty arranging  
transportation

6. You do not qualify for services you  
want to access

7. You have difficulty remembering  
and locating the services needed

8. You are still waiting for the  
service(s) that you need

9. You are stressed and/or frustrated  
in finding services

10. You do not know where to find  
help

11. You have financial issues that  
make it hard to access services



## **Appendix E**

### **Telephone script**

I am Gladys Hrabí, a Master of Social Work graduate student from University of Manitoba conducting a research project as part of my degree requirements under the supervision of Dr. Sid Frankel. Would you have a few minutes to discuss a research project now? (Alternatively, I could call back at a more convenient time.) This research study explores the experiences of brain injury survivors in accessing health and social services.

I have a few questions to ask to see if you are eligible for the study (use demographic questionnaire see Appendix C).

Results from the study will contribute to the scholarship of disability studies, healthcare access, social services provision, and health service policies. The study addresses the limited research on the lived experiences of brain injury survivors.

May I send you an electronic version of the recruitment poster? What is your email addresses? Do you mind if I send you a copy to share to someone you know who might be interested? Thank you so much for your time.

## Appendix F

### INTERVIEW GUIDE

#### INTRODUCTION:

*Thank you for agreeing to participate in this research project. I will review the informed consent and the process before you sign it. With your permission the interview will be recorded and transcribed for analysis. I will be asking you for a pseudonym which will be used to protect your privacy in the written portion of this research. Feel free to ask any questions before, during or after our interview session and you can withdraw from this research project at any time. You may refuse to answer question at any time. Do you have any questions before we begin?*

*Let's begin with your choice of a pseudonym and it is important to remember that none of this information will be used in ways that break confidentiality protocols.*

| <b>Questions</b>   | <b>Andersen's<br/>Behavioural Model</b> | <b>Critical Disability<br/>Theory</b>    |
|--|---|--|
| 1. When was the last time you used the health care system? Tell me about the experience. | Need (perceived)                        | Power<br>Insider's Knowledge<br>Language |
| <i>Probes:</i>   |   |  |
| <i>- How long did you have to wait for the appointment?</i>                              |   |  |
| <i>- How did you decide that you needed health care?</i>                                 |   |  |

2. Was there ever a  
time that you felt  
that you needed  
health and social  
services but didn't  
receive it?

3. How hard was it  
for you to find the  
services that you need?

4. How much did  
you feel that you  
were able to  
express what you  
wanted in your  
care?

5. How often did your  
service provider  
use technical  
language or  
jargons that made  
it hard for you to  
talk to him or her?

Can you give me  
an example?

6. Did the provider  
treats you as an  
equal? What did  
your provider does  
that made you feel  
equal?

7. If you were asked

questions, did you  
feel that you were  
listened to? In  
what way?

8. Who do you think  
has the most  
power in deciding  
about your care?

9. Tell me about a  
good/bad  
experience with  
the health and  
social services.

Contextual  
Characteristics

Power  
Insider's knowledge  
Language

What things made  
this a good/bad  
experience?

10. How much did you  
feel that the  
service provider(s)  
took account of  
any cultural factors  
that may have  
influenced your  
condition?

11. To what degree  
did the service  
provider see you  
as having useful  
knowledge of your  
brain injury?

12. Were you treated

differently because  
of your  
gender/employment  
status/ race/  
education?

13. How did your  
income level  
affected the  
service that you  
receive?

14. What things make  
it easier/harder to  
get and use health  
and social  
services?

Contextual  
Characteristics

Knowledge  
“Othering

*Probes:*

*How is brain injury  
viewed in your  
community/family?*

*Were you  
informed about the  
services available  
for someone with  
a brain injury?*

15. Think back to your  
encounter with  
social workers and  
the social service  
system.

Access to Health Care  
Contextual characteristics

What do you think?  
of the services you  
received?

Do you think the  
social worker has  
knowledge about  
brain injury?

How can social  
workers best  
support your  
access to care?

16. What do you think  
about when I say  
"access to  
health"? access to  
services?

Access to Health care  
Contextual  
Characteristics

Power  
Systemic structures

Probes:

*Do you think you have good access  
to healthcare or poor access to  
health care?*

*Were you satisfied with?  
the care that you  
received?*

*Do you think the health care system  
and its  
policies have the ability to*

*meet your health care  
needs?*

WRAP UP

Is there anything else I should know?

Is there anything that you  
want to ask me?

**Appendix G****RECRUITMENT POSTER****PARTICIPANTS NEEDED!****ACCESS TO CARE FOR  
ACQUIRED BRAIN INJURY (ABI) SURVIVORS**

We are looking for adults living with an acquired brain injury (ABI) to take part in a study of access to care in Manitoba. The aim of the study is to learn about your lived experiences in accessing health and social services, the barriers and facilitators you encountered, and factors that would improve your experiences in accessing care in Manitoba.

As a participant in this study, you would be asked to participate in a 60-90-minute face-to face or telephone interview.

Your participation is entirely voluntary. In appreciation of your time, you will receive a \$15 Tim Hortons or Real Canadian Superstore gift card.

To learn more about this study, or to participate in this study, please contact:

**Gladys Tabal- Hrabi**



[tabalg@myumanitoba.ca](mailto:tabalg@myumanitoba.ca)



This study is supervised by

Dr. Sid Frankel

Phone: [REDACTED] email: [sid.frankel@umanitoba.ca](mailto:sid.frankel@umanitoba.ca).

This research study has been approved by the Psychology/Sociology Research Ethics Board at the University of Manitoba



**Appendix H**  
**CONSENT FORM**



UNIVERSITY  
OF MANITOBA

Research Project Title: **Access to Care for Acquired Brain Injury survivors: A critical qualitative inquiry**

Principal Investigator and contact information:

Gladys Tabal-Hrabi. Phone [REDACTED] [tabalg@myumanitoba.ca](mailto:tabalg@myumanitoba.ca)

Faculty Advisor:

Dr. Sid Frankel. Phone [REDACTED] for out of Winnipeg; email:

[REDACTED]

**To help you make an informed decision regarding your participation, this letter will explain what this research is about, the possible risks and benefits and your rights as research participant. If you have questions about the letter, please feel free to ask. You will be provided with a copy of this letter and the informed consent if you choose to participate in this study.**

**1. What is the research about?**

You are invited to participate in a study about care and service provision among brain injury survivors in Manitoba. The purpose of the study is to investigate the barriers and challenges that you face in accessing brain injury services.

This study is part of a Master's thesis as partial fulfillment of degree requirements.

## **2. What does participation involve?**

As a participant, you will be asked questions about your experiences accessing services as a brain injury survivor. I will conduct a telephone interview and ask questions related to your current social circumstances. Upon meeting the inclusion criteria, I will meet with you to assess your capacity to make an informed decision about participation. You will be asked to complete and sign an informed consent. A pre-interview questionnaire will be conducted to ask information about your injury and your use of health and social services. You will be asked to commit to one interview for 60 to 90 minutes. Should you require a shorter interview, a second interview will be scheduled. Interviews will be held over the telephone or in person when possible, at a place and time most convenient to you.

Your participation in this study is fully voluntary and if you choose not to participate, it will have no consequences for your receipt of services. You can refuse to participate, and you can refuse to answer any questions at any point of the interview or withdraw from the study at any time without consequence.

The participant should contact me immediately if he/she desires to withdraw from the study and inform me if he/she is willing to permit me to continue any other phase of the research as outlined on the informed consent form. The researcher is allowed to keep, use, analyze, and study data already collected prior to removal from the study to protect the integrity of the research unless the participant requests that collected data be destroyed or excluded from data analysis. If the participant requests that collected data be destroyed or excluded from data analysis, data collected from the participant will not be used, and the researcher will

delete the data and destroy the audio recordings of the participant upon completion of the study. However, three (3) months after data have been collected (February 2020), participants cannot withdraw their consent after that time.

For participation in this study, each participant will receive a \$15.00 gift card as appreciation of your time given to complete the interview.

### **3. What are the risks in this study?**

For most people the experience of living with a brain injury as a survivor is an upsetting and life-changing event. Participating in this study may stir the emotional experience associated with the event. To limit the negative impact, if a question or discussion makes you uncomfortable, you can choose not to answer.

There is minimal risk involved in participating in the research study. If you disclose any risk to yourself because of participating in this study, I will inform your family members and/or service providers. You may also contact professionally trained counsellor at Klinik (204-786-8686), Crisis Response Centre (204-949-1781), and Community Mental Health Services (204-788-8330).

### **4. Will my information be kept confidential?**

In order to best represent what you convey throughout the interview, the interview will be audiotaped. However, you have the option of choosing not to be audiotaped, in which case I will take notes during the interview session. If you allow recording, each digital file will be destroyed after transcripts have been completed.

All identifying information such as name and contact information will be removed from transcripts, as well as any third parties mentioned in your interview. The transcribed data will be kept on a password-protected flash drive, which will be kept in a locked drawer in my home office. Only myself, my supervisor and the Research Ethics Board will have access to

the transcripts. I will destroy all transcripts three months after the completion of the thesis and your name will not be shared with anyone.

To minimize the risk of identification, you can choose a pseudonym or I will assign you one, and this pseudonym will be used throughout the study to represent your data. When the study is presented or written up, no information that identifies you will be included. Your name will not appear on any of the documents, except the consent form which will be kept at all times in a locked drawer which I only have access.

I will include some portions of our interview such as passages and direct quotes in my research findings and final thesis, and possible future publications. If you wish, you have the opportunity to review a summary of the research findings that are drawn from your interview, and let me know if there are any portions of the findings that you feel could make your recognizable to potential readers, of which I will remove. Despite the precautions set in place, some people who know you may guess your identity on your quotations.

### **CONSENT**

I have read the information presented in the information letter about a study by Gladys Tabal-Hrabi, under the supervision of Dr. Sid Frankel. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions and any additional details.

I was informed that participation in the study is voluntary and I can withdraw this consent by informing the researcher.

☐ I agree to participate in an audio-recorded interview for this study.

☐ I give permission for the use of anonymous quotations in any thesis or publication that comes from this study.

**If you wish to review the section of the findings based on your data to ensure that your privacy is protected, please check the following:**

☐ Yes, I would like to receive a copy of this study through email. My email address is: \_\_\_\_\_.

**OR**

☐ I would prefer to receive a copy of this study by regular mail. My mailing addresses is: \_\_\_\_\_.

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities.**

**The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.**

**This research has been approved by the Psychology/Sociology Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.**

**Signed** \_\_\_\_\_

**Print** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Appendix I

### RECRUITMENT SCRIPT

My name is Gladys Hrabí, and I am a Master of Social Work student from University of Manitoba. I am conducting a research study called **Access to Care for Acquired Brain Injury survivors: A Qualitative Inquiry** under the supervision of Dr. Sid Frankel.

The purpose of this study is to provide an opportunity for brain injury survivors to express their experiences in accessing health and social services. Knowledge and information generated from this study may help service providers improve the quality of service provision, as well as helping us to understand the needs of brain injury survivors as experts on their own condition.

I am meeting with you to invite you to participate in an individual interview in which you will be asked questions regarding yourself, your injury, and your experiences accessing brain injury services. Participation will require 60-90 minutes of your time and will be held at a mutually agreed location. You will also be provided an option to conduct the interview over the telephone, if this is deemed more convenient for your situation.

You may participate in this study if you are (1) 18 years of age and older, (2) residing in Manitoba (3) have an acquired brain injury at least 2 years prior; inclusive of traumatic, mild traumatic and non-traumatic brain injuries, (3) able to speak and understand English well enough to participate in an interview, and (4) having accessed some level of services from the health care system and social services over the past 12 months.

If you would like to participate in this research study, please contact me to arrange a telephone interview. Do you have questions now? If you have questions later, please contact me at [tabalg@myumanitoba.ca](mailto:tabalg@myumanitoba.ca)

If you know anyone who may be interested in participating in this study, please give him or her a copy of this information.

Thank you taking the time for considering my request.

## **Appendix J**

### **DEBRIEFING SCRIPT**

Thank you for participating as a research participant in the present study concerning your experiences accessing social and health care services in Manitoba.

I would like to ask you how you feel about the interview? Is there something that made you upset? Please let me know how I can help you.

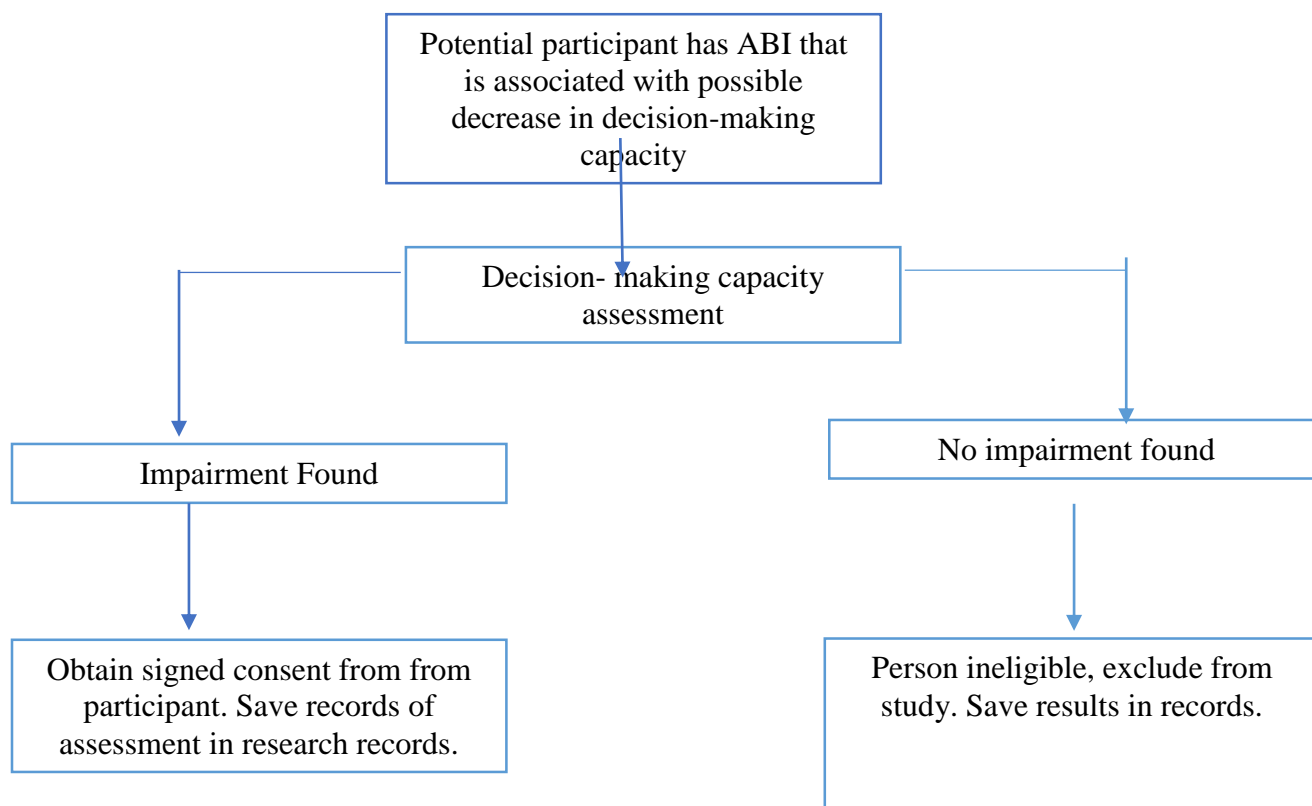
If you know of any friends or acquaintances that are eligible to participate in this study, I request that you do not discuss it with them until after they have had the opportunity to participate. Prior knowledge of questions asked during the study can invalidate the results. Your cooperation is greatly appreciated.

If you have any questions regarding this study, please feel free to ask the researcher at this time or you can email me at [tabalg@myumanitoba.ca](mailto:tabalg@myumanitoba.ca) or call me at [REDACTED]. You can also contact my supervisor Dr. Sid Frankel at [REDACTED] [REDACTED] for out of Winnipeg or email at [sid.frankel@umanitoba.ca](mailto:sid.frankel@umanitoba.ca). A copy of the summary of results will be sent to you through the method of your choice (email or regular mail).

In the event that you feel psychologically distressed by participation in this study, I encourage you to contact any of the following organizations:

1. Klinik (204-786-8686)
2. Crisis Response Centre (204-949-1781)
3. Community Mental health Services (204-788-8330)

**Appendix K**  
**DECISIONAL TREE**





**Appendix L****LIST OF ORGANIZATIONS TO SEND RECRUITMENT LETTER**

- 1. Selkirk Mental Health Centre- Acquired Brain Injury Program**
- 2. Southern Health Mental Health Transition**
- 3. St. Amant- ABI program**
- 4. Therapy First**
- 5. Transitional Living Centre**
- 6. VitalLife**
- 7. Workers Compensation Board- Long Term Injury**
- 8. WRHA Health Coordination**
- 9. Action Marguerite- ABI unit**
- 10. Block Building Therapies**
- 11. Pan-am concussion clinic**
- 12. Centre for Adult Psychiatry**
- 13. Centre for Geriatric Psychiatry**
- 14. CMHA- Winnipeg**
- 15. CMHA- Interlake Eastern**
- 16. E-rehab**
- 17. Aboriginal Wellness Centre**
- 18. Addictions Foundations of Manitoba**
- 19. Health Science Centre-Neurosurgery**
- 20. Interlake Eastern RHA**
- 21. Manitoba Health**
- 22. Northern Health Transitional Residence**
- 23. Post-Acute Neurosurgery Unit – Concordia Hospital**
- 24. Prairie Mountain Health- Brandon**
- 25. Riverview Health Centre- Stroke Unit**
- 26. Riverview Health Centre- ABI unit**
- 27. Seven Oaks General Hospital**
- 28. Willow Centre**

- 29. Corrections Centre**
- 30. Elizabeth Fry Society of Manitoba**
- 31. Victims Compensation Services**
- 32. Worker's Advisory Board**
- 33. Claimant's Advisor Office**
- 34. Manitoba Public Insurance- Long-term**
- 35. Brandon Support group**
- 36. Selkirk Support group**
- 37. Steinbach Support group**
- 38. Dauphin and Parkland support group**
- 39. March of Dimes**
- 40. Stroke Recovery Association**
- 41. Heart and Stroke Organization**
- 42. Society for Manitobans with Disabilities**
- 43. Deer Lodge Rehabilitation- ABI unit**
- 44. Movement Centre of Manitoba**
- 45. Independent Living and Resource Centre**
- 46. STARS Air ambulance**
- 47. EIA Centralized Services**
- 48. Manitoba League of Persons with Disabilities**
- 49. Disabilities Issues Office**
- 50. Manitoba Housing**
- 51. Fairfax Community Resources Inc.**
- 52. Society for Manitobans with Disabilities-Interlake Regional Office**
- 53. Brematson Disability**
- 54. Sport Manitoba concussion program**
- 55. Manitoba Hydro**

**Appendix M****COPYRIGHT AGREEMENT WOLTERS KLUWER HEALTH**

This Agreement between Gladys Hrabí ("You") and Wolters Kluwer Health, Inc. ("Wolters Kluwer Health, Inc.") consists of your license details and the terms and conditions provided by Wolters Kluwer Health, Inc. and Copyright Clearance Center.

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| Number of figures/tables/illustrations                  | 1  |
| Author of this Wolters Kluwer article                   | No   |

|                                    |   |
|------------------------------------|---|
| Will you be translating?           | No  |
| Intend to modify/adapt the content | Yes   |
| Title                              | Access to Care for Acquired Brain Injury<br>Survivors: A critical inquiry |
| Institution name                   | University of Manitoba  |
| Expected presentation date         | Oct 2020  |
| Portions                           | Figure 1 p. 651<br><br>University of Manitoba<br>28 Hathway Road          |
| Requestor Location                 | Winnipeg, MB R2G 2P5<br>Canada<br>Attn: University of Manitoba            |
| Billing Type                       | Invoice<br><br>University of Manitoba<br>28 Hathway Road                  |
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**Appendix N**  
**COPYRIGHT AGREEMENT WORLD HEALTH ORGANIZATION (WHO)**

**From:** "[permissions@who.int](mailto:permissions@who.int)" <[permissions@who.int](mailto:permissions@who.int)>

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Kind regards,

WHO Permissions team

## Appendix O

|  |  |  |                              |                           |
|--|--|--|------------------------------|---------------------------|
|  <p><b>UNIVERSITY<br/>OF MANITOBA</b></p>   | <p><b>Research Ethics<br/>and Compliance</b></p> | <p><b>Human Ethics</b><br/>         208-194 Dafoe Road<br/>         Winnipeg, MB<br/>         Canada R3T 2N2<br/>         Phone +204-474-7122<br/>         Email: <a href="mailto:humanethics@umanitoba.ca">humanethics@umanitoba.ca</a></p> |                              |                           |
| <p><b>PROTOCOL APPROVAL</b></p>  |  |  |                              |                           |
| <p><b>TO:</b> Gladys Tabal-Hrabi (Advisor: Sid Frankel)<br/>Principal Investigators</p>  |  |  |                              |                           |
| <p><b>FROM:</b> Jonathan Marotta, Chair<br/>Psychology/Sociology Research Ethics Board (PSREB)</p>   |  |  |                              |                           |
| <p><b>Re:</b> Protocol #P2019:142 (HS23395)<br/>"Access to Care for Acquired Brain Injury Survivors: A Qualitative Inquiry"</p>  |  |  |                              |                           |
| <table border="0" style="width: 100%;"> <tr> <td style="width: 50%;">Effective: November 26, 2019</td> <td style="width: 50%;">Expiry: November 26, 2020</td> </tr> </table>   |  |  | Effective: November 26, 2019 | Expiry: November 26, 2020 |
| Effective: November 26, 2019   | Expiry: November 26, 2020                        |  |                              |                           |
| <p>Psychology/Sociology Research Ethics Board (PSREB) has reviewed and approved the above research. PSREB is constituted and operates in accordance with the current <i>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans</i>.</p>   |  |  |                              |                           |
| <p>This approval is subject to the following conditions:</p>   |  |  |                              |                           |
| <ol style="list-style-type: none"> <li>1. Approval is granted for the research and purposes described in the application only.</li> <li>2. Any modification to the research or research materials must be submitted to PSREB for approval before implementation.</li> <li>3. Any deviations to the research or adverse events must be submitted to PSREB as soon as possible.</li> <li>4. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.</li> <li>5. A Study Closure form must be submitted to PSREB when the research is complete or terminated.</li> <li>6. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba <i>Ethics of Research Involving Humans</i>.</li> </ol> |  |  |                              |                           |
| <div style="border: 1px solid black; padding: 5px;"> <p><b>Funded Protocols:</b></p> <ul style="list-style-type: none"> <li>- Please e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer at <a href="mailto:researchgrants@umanitoba.ca">researchgrants@umanitoba.ca</a></li> </ul> </div>   |  |  |                              |                           |
| <p>Research Ethics and Compliance is a part of the Office of the Vice-President (Research and International)<br/> <a href="http://umanitoba.ca/research">umanitoba.ca/research</a></p>   |  |  |                              |                           |